

LIVING WITH LIMB LOSS: INDIVIDUALS'
AND PROSTHETISTS' PERCEPTIONS OF
AMPUTATION, PROSTHESIS USE AND
REHABILITATION.

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Abstract

Loss of limb through amputation presents a significant, life changing, circumstance for individuals. The prosthetist as the gate keeper to the health-care system and the facilitator of rehabilitation is essential to positive adjustment post-amputation. As yet, however, commonalities and differences in the understandings of each of these parties of the experience of limb loss, prosthesis use and rehabilitation remain unexamined. This comparison provides the focus for this study.

Fifteen individuals post amputation and 13 prosthetists were interviewed on their perceptions of limb loss and prosthesis use. Semi structured interviews were conducted, face to face, via telephone or via email. Data were audio-recorded and transcribed as necessary and thereafter analysed using Interpretative Phenomenological Analysis (IPA) in order to gain an understanding of the subjective experiences of individuals with limb loss and of prosthetists of the post-amputation process.

Analysis of the data led to identification of four key themes, namely Personal Identity, Social Identity, The Prosthesis and Communication. These themes were relevant for both groups. The meanings that they held for the two groups, however, differed in relation to key elements of the post-amputation experience.

Both groups have a shared interest in the process of prosthetic limb fitting and rehabilitation and yet come from very differing perspectives. The fitting and use of a prosthetic device is not a simple, technical process but rather involves a combination of psychological, social and practical components all of which must be recognized in the rehabilitation process. The differing expectations and understandings held by both groups become especially evident in interactions between individuals with limb loss and prosthetists. Communications between members of these groups can provide a central point for addressing differences in their understandings of living with limb loss and might provide a focus for further developments in research and practice.

Key words: Amputation, Prosthetics, Patient-Practitioner Communication, Identity, Interpretative Phenomenological Analysis.

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Table of Contents

Abstract	i
Acknowledgements	ii
Chapter1: Introduction	vi
Thesis outline	9
Chapter 2: Literature Review	11
Psychosocial impact of amputation	11
Affective distress and reaction to amputation	12
Body image anxiety and social functioning	14
Maintaining and managing identity	17
Social support and coping strategies	21
Patient-practitioner relationships	25
Chapter Summary	30
Chapter 3: Methodology	33
Phenomenological Psychology	33
Interpretative Phenomenological Analysis	35
Study Design	37
Ethical considerations	40
Participant recruitment	42
Data collection	46
Devising interview schedule	47
Face to Face interviews	47
Telephone interviews	48
Email interviews	49
Transcription	50

Analysis	51
Chapter 4: Personal Identity	55
Introduction	55
Prosthetists' Experience	57
Identity following amputation	57
Individual attitude and adjustment	60
Defining normality	61
Individuals' Experience.....	65
Identity following amputation	65
Individual attitude and adjustment	73
Defining normality	76
Chapter Summary.....	79
Chapter 5: Social Identity	84
Introduction	84
Prosthetists' Experience	85
Social interaction.....	85
Social support.....	88
Social comparison	91
Individuals' Experience.....	95
Social interaction.....	95
Social support.....	102
Social comparison	105
Conclusion.....	110
Chapter 6: The Prosthesis	113
Introduction	113

Prosthetists' Experience	114
Expectations of prosthesis use.....	114
Living with the prosthesis	119
Priorities for prosthesis use	124
Individuals' Experience.....	127
Expectations of prosthesis use.....	127
Living with the prosthesis	132
Priorities for prosthesis use	140
Chapter summary	143
Chapter 7: Communication.....	146
Introduction	146
Prosthetists' Experience	147
Prosthetist and patient interactions	147
Expectations of the system	152
Role of the prosthetist.....	157
Individuals' Experience.....	162
Prosthetist and patient interactions	163
Expectations of the system	170
Role of the prosthetist.....	173
Chapter summary	177
Chapter 8: Discussion.....	181
Personal identity	182
Social identity.....	187
The prosthesis.....	193
Communication	199

Suggestions for practice	205
Suggestions for future research	208
Study limitations and researcher reflections.....	209
Conclusions	213
References	214
Appendices	228
Appendix 1 – Interview Schedule , Individuals living with limb loss.....	228
Appendix 2 – Interview Schedule, Prosthetists	229
Appendix 3 – Recruitment advert from Individuals living with amputation.....	230
Appendix 4 – Information sheet for Individuals living with amputation, Face to face interviews.....	231
Appendix 5 – Information sheet for Individuals living with amputation, Email interviews.....	233
Appendix 6 – Recruitment flyer, prosthetists.....	235
Appendix 7 – Information sheet for Prosthetists, Face to face interviews.	236
Appendix 8 – Information sheet for Prosthetists, Email interviews.....	238
Appendix 9 – Project Consent Form	240

List of tables

Table 1: Demographic data of individuals living with amputation.....	45
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Chapter1: Introduction

This study is concerned with the exploration of the perspectives of individuals living with amputation and of prosthetists on limb loss, prosthesis use and rehabilitation. Each year in the UK more than an estimated 5000 individuals are subjected to limb amputation (NASDAB, 2005). Of these amputations more than 90% are unilateral, lower limb amputations (NASDAB, 2005). The experience of individuals undergoing amputation is likely to be complex as the circumstances surrounding the amputation and subsequent rehabilitation involve a variety of physical, psychological and social reasons and outcomes. In the majority of cases the amputation is performed as a life-saving or life-extending treatment following a debilitating condition or traumatic event.

Research in this field has highlighted a number of areas of psychological concern such as affective distress, coping styles, influences on adjustment (Atherton & Robertson, 2006; Breakey, 1997b; Desmond & MacLachlan, 2002; Gallagher & MacLachlan, 1999). These attempts to predict the individual's reaction to limb loss have shed some light on the complex nature of this experience. However, these studies are limited in terms of providing an understanding of the experience from the individuals' perspective. Following the identification of the need for a more personal account of limb loss and prosthesis use (Dunn, 1994; Dunn, 1996; Gallagher & MacLachlan, 2001; Gallagher & MacLachlan, 2001), a number of studies have attempted to explore particular aspects of the meaning of limb loss with particular focus on such aspects as coping strategies, phantom limb perceptions and changes to self-identity (Bosmans, Suurmeijer, Hulsink, Geertzen, & Dijkstra, 2007; Senra, Oliveira, Leal, & Vieira, 2012; Sjö Dahl, Gard, & Jarnlo, 2004). A full exploration of the experience of losing a limb and living with a prosthetic device from the perspective of the individual is still needed in order to gain a subjective understanding of this phenomenon. This has been partially explored through a series of studies investigating the experience of

limb loss and prosthesis use from a phenomenological perspective (Hamill, Carson, & Dorahy, 2010; Liu, Williams, Liu, & Chien, 2010; Murray, 2004; Murray, 2005; Murray, 2009; Saradjian, Thompson, & Datta, 2008).

The process of post amputation recovery inevitably takes place at least partially within the clinical setting of a rehabilitation centre. The replacement of an amputated limb with a prosthetic device and the successful integration of this device into the individual's daily life forms a central role in the rehabilitation process. While an understanding of the individual's experience of limb loss and subsequent prosthesis use is vital, further exploration of the perspectives of the prosthetists involved in this clinical rehabilitation is lacking. Much of the experience of limb loss and prosthesis use will be reflected in, and potentially influenced by, the dyadic relationship between individual and prosthetist in which the individual becomes a patient. Studies considering the patient-practitioner relationship have looked at a variety of health circumstance and have found that difficulties in communication or a lack of shared understanding can be detrimental to the patient (Chew-Graham & May, 2000; Hordern & Street, 2007a; Ononeze, Murphy, Macfarlane, Byrne, & Bradley, 2009; Ostlie, Dale, & Moller, 2007; Pun, Coates, & Benzie, 2009). In relation to the specific relationship of prosthetists and individuals with lower limb amputation, research in this area is limited to a small number of studies concerned with the practicalities of prosthesis prescription (Schaffalitzky, Gallagher, MacLachlan, & Ryall, 2011) and phantom limb pain (Mortimer, Steedman, McMillan, Martin, & Ravey, 2002; Mortimer et al., 2004). Several studies have revealed areas of the patient-prosthetist relationship which individuals found to be less than satisfactory including overall communication and interpersonal skills and the exchange of information (Murray, 2013; Nielsen, 1991; Pezzin, Dillingham, MacKenzie, Ephraim, & Rossbach, 2004; Van Der Linde, Hofstad, Geertzen, Postema, & van Limbeek, 2007).

While the perspective of individuals who have lost a limb in this regard has been considered to a degree, there has been no research to date which has considered the

prosthetists' perspective and the impact that this and the perspective of those who lose a limb may have on each other. This study intends to offer further insight into the lived experiences of individuals who have lost a limb but crucially also into the perspectives of prosthetists with regard to the experience of limb loss, prosthesis use and rehabilitation. These findings will be discussed in terms of their impact on each other, the augmentation of our understanding of the phenomenon of living with limb loss, prosthesis use and the potential implications for clinical practice.

Thesis outline

Chapter 2 presents a review of literature to date in this area highlighting both critical findings and areas of neglected research. This chapter offers a justification for the need to consider the meaning and understanding that an individual has of their experience and the value to be gained from such knowledge from prosthetists' perspective. In addition it highlights the importance of the patient-practitioner relationship and the lack of research therein in this field.

Chapter 3 contains information of the research approach and design. This chapter develops the rationale for the use of a phenomenological approach and in particular Interpretative Phenomenological Analysis. The research procedure for the current study is then presented.

Chapters 4 to 7 detail the empirical findings of this study combining both the experiences of individuals living with amputation and prosthetists. These experiences are detailed separately and then compared and discussed. The chapters deal with specific themes of Personal Identity, Social Identity, The Prosthesis and Communication.

Chapter 8 provides a discussion of the key findings of this study. Implications of findings for clinical practice are presented as well as suggestions for future research. In

addition researcher reflections on the research process and potential limitations of the study are examined¹.

¹ Following careful consideration of both the views of the participants in this study as well as current literature I decided against using any defining terminology such as “amputee” and instead opted for the more inclusive “individual living with limb loss”. A notable exception to this is where prosthetists are discussing the individuals in terms of their part in the clinical process in which case the term “patient” may be used to indicate the prosthetists’ perceptions at this time. The term “patient” is also used in discussing patient-practitioner interactions.

Chapter 2: Literature Review

Psychosocial impact of amputation

The study of the psychological, social and behavioural components of post amputation rehabilitation and prosthetic use has been recently termed *Psychoprosthetics* (Gallagher, Desmond, & MacLachlan, 2008). This concept offers an interdisciplinary approach to both clinical and research aspects of amputation and prosthetic use. By studying the impact of the social, psychological and environmental factors on the experience and rehabilitation of post amputation individuals the potential for a more holistic and person centred approach is offered. Attempts to understand this multifaceted experience have traditionally focused on the quantitative analysis of contributory variables to the adjustment to amputation and successful use of a prosthetic device. This area has however developed in recent years to include recognition of the need for a fuller understanding of the experience of limb loss.

This review provides an overarching appraisal of the significant factors that have been found to play a role in the experience of limb loss and prosthesis use. Firstly the psychosocial impact of amputation is discussed with specific reference to key areas of interest. Initial reactions to amputation will be explored along with the prevalence of affective distress within individuals following amputation. Following this the role of body image anxiety and social functioning will be examined. Perceived social stigma and a desire to maintain a personally acceptable identity leads on to wider aspects of managing both personal and social identities. Finally the role of social support and coping strategies in the adjustment process are considered. Following discussion of the personal and social experiences of individuals living with amputation, the role of the prosthetist in the process is considered with particular emphasis on the patient-practitioner relationship. Aspects of this relationship have been highlighted through other healthcare areas however there appears to be a dearth of such research in the area of amputation experience. To this end, the need to

address this relationship in the area of prosthetic rehabilitation is underlined and the implications for clinical practice emphasised.

The literature presented here is by no means a comprehensive review of the complete body of work available in the area of psychological aspects of amputation and prosthesis use. Rather it is intended to highlight pertinent areas used in developing the rationale for this study. This review presents the need for a subjective account of this experience from an insider's perspective. In addition, the importance of the patient and prosthetist relationship, the current lack of research available in this area and the potential implications of this relationship on the rehabilitation process are highlighted.

Affective distress and reaction to amputation

A large body of research has considered the psychological consequences of amputation with a particular focus on affective distress. These studies allow us to begin to build a picture of the experience of individuals who find themselves in this set of circumstances. There appears to be ample evidence to suggest that increases in anxiety and depression are common in a post amputation sample (Atherton & Robertson, 2006; Coffey, Gallagher, Horgan, Desmond, & MacLachlan, 2009; Desmond & MacLachlan, 2006a; Horgan & MacLachlan, 2004; Singh et al., 2009). Potential difficulties with the reported rates of anxiety and depression within this group have been cited as revolving around the methodological differences of such studies in terms of the cross-sectional designs utilised as well as differences in measures or classification points while using the same measure (Horgan & MacLachlan, 2004). Despite this, this particular group of empirical papers all present compelling evidence for increased affective distress than would be expected in the general population using the same measure and same classification scale (Hospital Anxiety and Depression Scale, HADS, (Zigmond & Snaith, 1983), even with the use of a more conservative cut-off point as used by one set of authors (Atherton & Robertson, 2006). A recent longitudinal study assessing presence of depressive and anxious symptoms found that

while such symptoms had appeared to reduce quickly following amputation these were found to have increased at a second time point, 2 years following discharge (Singh et al., 2009). While negative affect appeared to resolve during in-patient rehabilitation, the increased reporting at follow up does lead to questions as to why this may be the case. Similarly, further studies questioning the prevalence of affective distress except in very specific groups of young, traumatically amputated individuals lead to questions regarding the circumstances surrounding the presence of such symptoms (Fisher & Hanspal, 1998; Frank et al., 1984). Suggestions of less support at home than in an in-patient setting, reduced confidence in own ability and need for continued professional physical and psychological support may offer some tentative conclusions (Coffey et al., 2009; Desmond & MacLachlan, 2006a; Singh et al., 2009). However the lack of a true understanding of the patients' experience renders these merely speculative.

Depression and anxiety have been found to correlate with such outcomes as functional and social restriction, general adjustment, social adjustment, appearance related beliefs and social or activity restrictions in quantitative studies (Atherton & Robertson, 2006; Coffey et al., 2009; Williamson, Schulz, Bridges, & Behan, 1994). While attempts have been made to quantify and predict such relationships, uncovering the individual meaning behind these reactions is essential in understanding the experience of limb loss. Qualitative research on the experience of amputation has been able to indicate common themes in individuals' reactions. These themes include reactions of grief, anger, sadness, shock, guilt, isolation and vulnerability in addition to the depressive and anxious symptomology as found in previous studies (Liu et al., 2010; Rybarczyk, Edwards, & Behel, 2004; Senra et al., 2012; Sjö Dahl et al., 2004). Symptoms of depression were related to a sensation of isolation and dependence on friends and family (Senra et al., 2012). In addition, the dramatic and sudden nature of the incident contributed to feelings of shock and frustration (Liu et al., 2010). Such research provides a more nuanced understanding of reactions to amputation than those studies which

focus on the classification or prediction of outcomes. Qualitative research indicates that understanding the individual's circumstances is central to understanding the links between amputation and potential psychosocial distress rather than simply measuring symptoms in isolation.

Body image anxiety and social functioning

Alongside affective distress, the prevalence of body image concerns following amputation has been a major research focus. A common assumption is that the nature of amputation is such that individuals have to reconcile multiple body images including self-image pre and post amputation, with or without prostheses and their imagined or "ideal" image of themselves (Breakey, 1997a). In addition, changes to appearance as well as changes to functional ability force a renegotiation of their self-image (Rybarczyk, Nyenhuis, Nicholas, Cash, & Kaiser, 1995). A lack of adjustment to this new body image, both with and without prosthesis may lead to a variety of additional psychosocial and prosthesis related issues. Body image anxiety has been statistically correlated with a range of psychological variables such as increased depression and anxiety, decreased quality of life and self-esteem as well as decreased prosthesis satisfaction (Breakey, 1997b; Coffey et al., 2009; Murray & Fox, 2002; Rybarczyk et al., 1992; Rybarczyk et al., 1995). Appearance related beliefs are commonly based on self-report questionnaires which measure levels of satisfaction with one's appearance, with and without the prosthesis, in private and in public and in terms of contribution to self-image (Atherton & Robertson, 2006; Breakey, 1997b; Murray & Fox, 2002; Rybarczyk et al., 1995).

Again, in order to better understand the relationships between amputation, body image anxiety and affective distress it is helpful to examine the meaning that this particular aspect of amputation holds for the individual. One particularly salient aspect of body image anxiety which may go some way to explaining its importance in psychosocial adjustment to amputation is the role of perceived social stigma and the reaction of others. The role of both

perceived and real social stigma in the development of body image anxiety and the subsequent impact on adjustment to amputation has been demonstrated in a variety of quantitative studies (Atherton & Robertson, 2006; Behel, Rybarczyk, Elliott, Nicholas, & Nyenhuis, 2002; Rybarczyk et al., 1992; Rybarczyk et al., 1995; Rybarczyk & Behel, 2008). Indeed, the importance of concerns over the perceptions and reactions of others has been suggested as being central to the development of a new self-concept post amputation (Rybarczyk & Behel, 2008). Rybarczyk and colleagues (1992) reported that the combination of social discomfort, social support and perceived health provided the strongest contribution to scores of depression. A subsequent study found that body image was a significant predictor of depression, quality of life and prosthetist rated adjustment regardless of age, time since amputation or site of amputation (Rybarczyk et al., 1995). In addition, perceived social stigma was found to contribute significantly to depression. More recently, public but not private self-consciousness was found to positively correlate with affective distress, body image anxiety and psychosocial adjustment difficulties in a quantitative analysis (Atherton & Robertson, 2006). This suggests that both the experienced and anticipated reaction of others to the individual post amputation was more salient in the adjustment process than their own perception of themselves. Even individuals who report personal satisfaction with their appearance are seen to take steps to cover their amputation when in social settings; for fear that other people will be upset or disconcerted by it (Saradjian et al., 2008).

Not all studies found the desire of individuals to disguise or hide their amputation however. In some cases the opposite was true whereby attempts to “hide” the amputation was considered unnecessary and in some cases individuals felt compelled to deliberately show their prosthetic device, often in elaborate ways choosing to personalise and decorate their device in some way (Murray, 2009). This variety in attitude to the concealment and display of prosthetic devices may offer further insight in to the differing aspects of rehabilitation that are important on an individual level. As Murray (2009) indicates, those

who were happier to display their device often chose to do so as the cosmetic covering that would be needed to conceal it would detract from their functional ability. These individuals, therefore, prioritised function over aesthetics. Taken together, this evidence points to the importance not only of the satisfaction an individual has with their own body but also the impact that they feel this has on the reactions of others towards them. While factors such as anxiety, depression and body image are clear and perhaps more obvious targets for research, the inevitable overlap with the social experience appears to offer a central link to understanding this experience. As stated by Saradjian and colleagues (2008), the changes in self-image for individuals following amputation are “enmeshed within their social experience” (p.874). The way an individual feels about him or herself is of vital importance, however the perception they have of themselves in a social realm is also central to the adjustment process.

Difficulties in contending with the loss of a part of their body and reconciling this new appearance with their previous self-perception are presented as being initially distressing to the individuals with reactions of shock, anger and anxiety being common (Gallagher & MacLachlan, 2001; Rybarczyk et al., 2004; Sjö Dahl et al., 2004). However concerns regarding the perceptions and reactions of others to their physical difference appear to be superseded by their own perceptions as they begin to come to terms with their own appearance. In several studies, the desire to achieve a “normal” appearance was expressed as being paramount to the individual particularly with regards to the use of a prosthetic device (Gallagher & MacLachlan, 2001; Murray, 2009; Saradjian et al., 2008; Senra et al., 2012; Sjö Dahl et al., 2004). This “normal” appearance centres on their own self-perceptions but also being able to hide the amputation from others and to continue to function socially as they did prior to the amputation. Often when their amputation and physical differences were made apparent in social settings with both strangers and those known to the individual, the reaction of others were found to be difficult to cope with. These reactions were described as

patronising, awkward, embarrassing and often accompanied by staring or negative judgements on abilities over and above that which had been impacted upon by the amputation (Gallagher & MacLachlan, 2001; Hamill et al., 2010; Sjö Dahl et al., 2004). Often merely the fear of this reaction was enough to spur the desire to hide the amputation (Hamill et al., 2010; Sjö Dahl et al., 2004). The use of a prosthetic device often allowed the individual to hide their difference and thereby avoid such reactions and their potential negative connotations. This ability to hide an aspect of themselves was important, being described as offering “respite” from the daily difficulties of social interactions (Saradjian et al., 2008) and allowing the controlled revelation of their personal circumstances and management of such reactions (Gallagher & MacLachlan, 2001; Murray, 2009). The use of a prosthetic device to maintain not only a sense of personally acceptable self-image but also a socially presentable self has been shown to be central to the experience of individuals living with amputation and provides a narrative linking body image concerns to psychosocial outcomes.

Maintaining and managing identity

Many studies have highlighted the importance of managing personal and social aspects of identity following amputation (Hamill et al., 2010; Murray, 2005; Murray, 2009; Saradjian et al., 2008; Sjö Dahl et al., 2004). Individuals experience difficulties integrating their pre amputation self identity with that of their post amputation experience. To be treated as an individual first and foremost rather than defined by their disability was of great importance (Hamill et al., 2010; Sjö Dahl et al., 2004; Sousa, Corredeira, & Pereira, 2009). In renegotiating this sense of personal and social identity, individuals often had to redefine their own previously held perceptions of ability and disability. Often individuals had to redefine their prior views of disability so as to maintain a more favourable view of themselves. For example, individuals may reject aspects of their rehabilitation that are strongly associated with disability such as moving to an adapted bungalow (Hamill et al., 2010). Paradoxically,

devices which were previously viewed as belonging to a “disabled” category were subsequently redefined as “enabling” as their worth to the individual was recognised. An individual’s “normal” identity is facilitated and maintained by the function and appearance afforded them by the prostheses (Saradjian et al., 2008). Despite this however, the relationship with the prosthesis could be problematic with enabling aspects often being accompanied by practical and physical limitations such as pain, discomfort or limited mobility (Gallagher & MacLachlan, 2001; Saradjian et al., 2008; Senra et al., 2012; Sjö Dahl et al., 2004). Regardless of these problems, individuals were willing to accept such personal drawbacks in exchange for the social benefits that the prosthesis provided.

Socially inferred identities based on amputation and physical difference are often rejected as they do not necessarily correspond with the individual’s view of themselves. The social impact of amputation on identity is explained in one case as being not the presence of the amputation itself which leads to this “disabled” identity but the reaction of others in a social setting (Hamill et al., 2010). Similar discontent was expressed at the danger of the identity of “disabled” superseding any other identity with which the individual felt more comfortable with such as that of gender identity being replaced with the asexual categorisation of “disabled”. Society’s ascription of this often unwanted identity provides another explanation of the desire to hide the amputation using a prosthetic device (Hamill et al., 2010). Individuals attempted to counter negative perceptions by “proving” their ability and worth by challenging such assumptions through achievements often facilitated through prostheses use such as returning to work, maintaining leisure pursuits, or other physical achievements (Hamill et al., 2010; Murray, 2009; Saradjian et al., 2008). This focus on equal, functional ability may hold some of the key to understanding social and personal identity post-amputation.

Horgan and MacLachlan (2004) identify functional ability as being a potential key component to the renegotiation of identity and adjustment to amputation but suggest that, as

yet, this area is under researched. A potentially significant factor within this area is participation in activity. Several quantitative studies have reported that maintenance of physical activity is correlated with a decrease in body image anxiety (Tatar, 2010; Wetterhahn, Hanson, & Levy, 2002). However what is not clear is the direction of this effect; Are these people capable of being more active because they are more satisfied with their body image or are they more satisfied with their body image because their need for active roles are being fulfilled? While these studies highlight the impact of physical activity particularly in a sporting context, the links with restriction or participation of activity in an everyday context are equally compelling and perhaps more relevant to the majority of amputation patients. Restriction of daily activities (personal care, household chores, socialising) was found to predict greater occurrence of depressive symptoms as well as being associated with decreases in quality of life and social contact following amputation (Asano, Rushton, Miller, & Deathe, 2008; Williamson et al., 1994). Similarly, symptoms of affective distress, increased body image anxiety and decreased psychosocial adjustment have been found to be related to functional restriction, social restriction and lack of prosthetic functional satisfaction (Coffey et al., 2009).

The importance to an individual of being able to continue to participate in activities of daily living and socialisation may offer some examples of the aspects of rehabilitation that are of distinct relevance to individuals in this set of circumstances. Clearly, continued participation in daily and social activities is highly relevant following amputation. It has been shown that employment and daily prosthesis use were predictors of psychosocial adjustment (Sinha, van den Heuvel & Arokiasamy, 2014). Similarly, functional satisfaction with the prosthetic device was found to relate to both decreased body image anxiety and increased hours of use (Murray & Fox, 2002). Thus a functionally satisfactory prosthetic limb is likely to be pivotal to the completion of social roles. This proposal has been supported through a range of studies suggesting that the completion of social roles, be it

personal, occupational or otherwise, was important in adjustment to amputation and identifying prosthetic priorities (Murray, 2009; Rybarczyk et al., 2004; Saradjian et al., 2008). This functional ability and ability to complete personally relevant social roles equates to the achievement of self-efficacy and independence afforded by the prosthetic device. Feeling able to maintain a level of independent functioning and have less of a reliance on others to achieve goals produced a higher level of self worth in individuals and therefore a greater level of self assessed adjustment to amputation (Murray, 2009; Saradjian et al., 2008). The importance of this level of achievable, functional ability and its relation to independence and social roles in adjustment to amputation is a vital aspect of this experience with the unique needs of each individual having a role to play in the rehabilitation process. In some cases however the optimal functional and social goals of an individual may not be appropriate given the nature of their amputation and the technical limitations of their device. In such cases adjusting roles or expectations accordingly is required and this adjustment of expectations has been reported as being not only essential but as a positive outcome of rehabilitation (Hamill et al., 2010; Saradjian et al., 2008). Hamill and colleagues (2010) found that the ability to set and achieve appropriate goals gave the individual a sense of satisfaction, and allowed them to reassert their independence and control. This has been further supported in an additional study which found that those individuals who expressed life goals of high importance as well as those who showed a high level of ability to adapt goals according to circumstances (termed “goal disengagement”) showed lower levels of depressive symptoms and higher levels of general and social adjustment at six months post-amputation (Coffey et al., 2009). The disruption of goal achievement was found to predict higher levels of depression and lower levels of adjustment in the same time scale. They also reported that those life goals which were rated most highly were concerned with interpersonal relationships, independence and subjective well-being while the goals which were rated as being most hindered by amputation concerned physical limitations and disruptions in daily activities. Similarly the ability to shift life goals according to the current

situation has been suggested as being demonstrative of a determination to adjust to amputation with a reduced emphasis on physical qualities and an increase in the value of ones intrinsic values (Rybarczyk et al., 1995). The importance of functional ability and the completion of social roles appear to be of vital importance in the experience of individuals post amputation. However the ability to adapt functional expectations and goals in order to ensure that these goals are achievable also plays a role in adjustment to amputation and prosthesis use. The ability of individuals to adapt their goals where necessary is one of a battery of coping strategies which have been examined in this context. The use of other such strategies and the specific importance of social support will now be discussed in order to add further understanding to this experience.

Social support and coping strategies

Research studies have also investigated coping strategies and social support in relation to adjustment with these variables being viewed as both independent and interrelated. Several attempts have been made to quantify the impact of social support and coping styles on rehabilitative outcomes. Perceived social support following amputation was found to predict life satisfaction, pain interference and mobility irrespective of amputation or demographic factors (Williams et al., 2004). Social support was also listed as a predictor of participants' perceived quality of life after amputation (Asano et al., 2008). Hanley and team (2004) investigated the combined effects of social support and coping styles on long term adjustment to amputation. This attempt to understand the impact of the individuals' reactions to amputation and subsequent, long-term adjustment suggests that social support and catastrophizing (describing the pain and their situation in excessively negative terms) are related to increases in their adjustment measures while solicitous support (from a significant other) was related to decreases in adjustment. The authors explain this counterintuitive finding by suggesting that individuals who used catastrophizing as a coping strategy may have had more improvement to make than those who were already using positive strategies.

Avoidant coping strategies, while potentially useful in initial stages of rehabilitation, were found to be maladaptive to both physical and psychological well being. In addition individuals who exhibited high avoidance strategies in addition to low social support seeking behaviour were found to have lower adjustment while those with low social seeking behaviour and low avoidance strategies exhibited higher levels of adjustment (Gallagher & MacLachlan, 1999). The authors interpret these findings by stating that individuals who rely too heavily on social support from others do not find ways to self support, which in itself can be maladaptive even without avoidance strategies. An additional study investigating coping styles also identified avoidance as being a key contributor to psychological distress and poor psychosocial adjustment post amputation (Desmond, 2007). This is similar to the results of other studies which found that an over reliance on avoidant coping styles prevented individuals from using more active coping mechanisms, while those who used problem solving strategies were more likely to exhibit higher psychosocial adjustment and lower rates of depression (Desmond & MacLachlan, 2006b; Livneh, Antonak, & Gerhardt, 1999). Taken together, these studies point towards not only the impact of personal reaction and coping styles on adjustment to amputation but also of the importance of social support and the negative effect that may result in the absence of, or over-reliance on, such support.

Analysis of the origins of various coping strategies and the meaning that they hold for the individual provides a more in-depth understanding of this experience. Studies clearly show the use of social comparison as a major coping strategy for individuals. Through the comparison with other individuals with amputation, individuals are exhibiting the active coping strategies highlighted by Desmond (2007). The use of downward social comparison in which they compared themselves to individuals who they considered to be in a more negative situation than their own was common, as was adjusting sense of perspective to accommodate their situation in a more positive light (Hamill et al., 2010; Oaksford, Cuddihy, & Frude, 2005; Saradjian et al., 2008; Sjö Dahl et al., 2004). The need for positive social

support and in particular family and peer support is also highlighted. Discussions of psychological support, empathy and practical support are common as is the desire for acceptance as the same individual post-amputation (Hamill et al., 2010; Saradjian et al., 2008; Senra et al., 2012). Peer support from individuals who have shared the experience of limb loss are also classed as vitally important in the rehabilitation process. The ability to talk to someone who has shared the same experience offers individuals a level of support that their own social network is unable to provide (Hamill et al., 2010). Negative aspects of maladaptive support were also raised however, including solicitous or suffocating actions from family members who assume too great a role in the rehabilitation process and life of the individual (Hamill et al., 2010). In addition, in circumstances where social groups were found to treat the individual differently due to their amputation or where negative reactions were present this had a negative impact on the individual (Liu et al., 2010; Saradjian et al., 2008). While previous quantitative studies highlight the need for social support, the experiences shared here clearly highlight the nature of this support that is needed to be beneficial.

While the vast majority of studies focus on the presence of negative outcomes of amputation such as affective distress or a lack of support or effective coping strategy, a select number of studies focus on the positive outcomes and influences on adjustment to amputation and prosthesis use. Dunn (1994) presents a review of literature pertaining to the perception of positive meaning and beliefs after a negative life event, with particular focus on acquired disability. The concept of personal meaning refers to the positive assessment which people who find themselves in such a situation often use in order to make sense of their particular circumstances. This may involve attempts to answer questions about why the circumstances occurred and, in many cases, endeavouring to find a “silver lining” in an otherwise negative event (Thompson, 1985). Creating personally acceptable versions of the self and the circumstances within which the individual finds themselves allows the

individual to rationalise this otherwise negative event. The use of such positive meanings is thought to be protective and adaptive rather than being in any way problematic or denying of the circumstances. Such strategies provide methods of reality negotiation for these individuals and as such are more useful than detrimental.

Dunn (1996) empirically investigated the impact of these strategies on the adjustment of individuals following amputation. The results demonstrated that an ability to find positive meaning in their circumstances, maintaining a level of optimism and perceived control over the disability contributed to lower levels of depression. Similarly, higher levels of self-esteem were found in individuals who reported higher levels of optimism and perceived control. In terms of positive meaning, several sub categories were identified with the most prevalent being the identification of side benefits and reappraisal or redefinition of life post amputation.

The identification of the need for a focus on the potential impact of positive meaning following amputation was further developed by Gallagher and MacLachlan (2000). Their results associated the application of positive meaning following amputation to higher levels of health and physical capabilities, lower levels of reported activity restriction and higher levels of adjustment to amputation when compared to those who did not report any positive aspects. Further indications of the influence of positive perceptions of life following amputation are found in a more recent study which indicates that feelings of hope as well as higher levels of social support are related to an increase in levels of general adjustment (Unwin, Kacperek, & Clarke, 2009).

The importance of a positive attitude following amputation has been further endorsed through qualitative analysis of individual experiences. Developing a positive outlook on circumstances and taking ownership of adjustment and life in general were expressed as being important as illustrated by this individual “Disability is what you make of it...You’ve

just got to make the best you can” (Saradjian et al., 2008). Similar findings were illustrated where positive changes were reported in the lives of subjects who made the active decision to adopt a more optimistic attitude. Social support and coping strategies each appear to offer benefits to the rehabilitation of individuals following amputation (Liu et al., 2010). However, the nature of both of these factors should be considered in order to ensure that the impact on the individual has a positive effect. The nature of these strategies and the way in which they could be incorporated into rehabilitation needs further investigation in order to ensure maximum benefit for individuals facing amputation.

Patient-practitioner relationships

The potential for application of the psychosocial variables implicated in these studies to the rehabilitation process is vast. In order to assess properly how these variables may be incorporated into clinical practice an investigation of the understanding of the experience of amputation from within this process is needed. A lack of appreciation of the experience of the patient on the part of the clinical team may have potential to lead to detrimental outcomes for the patient. The understanding and experience of these professionals must be investigated and compared to that of the individuals who find themselves in this set of circumstances in order to determine the level of shared or discrepant understanding within this on-going interactive experience.

The comparison of patients’ and health care professionals’ perspectives has been investigated in a range of healthcare areas including chronic back pain (Chew-Graham & May, 2000), sociocultural influences on secondary cardiac behaviour (Ononeze, Murphy, Byrne, Bradley, & Macfarlane, 2006)), sexuality and intimacy following cancer (Hordern & Street, 2007a), juvenile arthritis ((Ostlie et al., 2007) and barriers to diabetic self-care (Pun et al., 2009). Each of these papers discusses aspects of similarity and discrepancy in the perceptions of these groups and details the clinical implications. Through exploring the

perceptions, opinions and related behaviours of both patients and practitioners in these differing settings, we are offered an insight into the potential impact that these similarities and differences may have on the patients' experiences. At the centre of these appears to be differences in emphasis regarding the understanding and meaning of particular aspects. Ononeze and colleagues (2006) discussed the shared and discrepant views of patients and practitioners and highlighted the discrepant views on the understanding that patients have of the disease process. While recognising this discrepancy, the practitioners appear to be placing blame for this lack of understanding with the patients rather than recognising their own role in enabling patients through their own communication. Similarly, ineffective communication and a lack of reflexive practice is emphasised in discussions of sexuality and intimacy following cancer (Hordern & Street, 2007a).

The perceptions expressed by the health professionals are found to be often based on assumptions of the experience of the patients with little or no attempt to clarify through patient discussions. Beyond these assumptions comes the admittance of the practitioners to feeling ill-prepared or personally uncomfortable to embark on such discussions therefore rendering the partnership with the patient as less than effective (Hordern & Street, 2007b). In addition, the lack of reflective practices and the application of their own personal assumptions or priorities within the clinical process as opposed to full disclosure and patient involvement are found to cause difficulties, with both groups expressing dissatisfaction with the relationship, the process and the outcomes. Barriers within the system are also highlighted as being at least partially responsible for the difficulties health professionals express in relations to such issues. A lack of training and an awareness of limitations of time and resources are cited as the root of differing priorities between these two groups (Hordern & Street, 2007b; Ononeze et al., 2006; Pun et al., 2009). This insight into the difficulties encountered and the need for a more supportive and inclusive patient practitioner relationship can be easily transferred to other healthcare settings. In their comprehensive

review of the literature detailing patient and provider experiences of barriers to self-care in type 2 diabetes, Pun and partners (2009) conclude that while healthcare professionals have the opportunity to improve patient understanding and enable successful self-care this is often impeded by systematic barriers and a discrepancy in the perceived importance of particular factors between patients and practitioners. Communication and collaboration are highlighted as being of key importance in facilitating a successful, mutually satisfactory relationship and outcomes. The largest discrepancies appear to centre on the focus of health professionals on medical and medicinal factors while patients are more concerned with personal, psychological barriers of a more personal relevance.

These studies underline the discrepancies in perceptions of the same issue between patients and practitioners and the influence that this may have on the clinical relationship and process. They recognise that aspects of communication, patient involvement and practitioner influence should be addressed in order to facilitate and enable a more collaborative relationship. The transferrable potential of these results for other healthcare relationships and the appreciation of the need to consider such discrepant meanings when applied to health related experiences offer an opportunity to consider such issues in the prosthetic rehabilitation process.

Research comparing patient and practitioner accounts of aspects of amputation and prosthesis use is limited, particularly with regard to the personal experience of limb loss. Schaffalitzky and associates (2011) investigated the experiences of prosthetic service users and providers regarding prosthetic prescription process and outcomes. While this study concentrates on perceptions of the service itself and particular aspects of prosthesis use, aspects of meaning, prioritisation and communication also come to the fore. Aspects such as balance, independence and the goal of successful prosthesis use are discussed as important for both users and providers. However, while the providers discuss these in far more physical rehabilitation terms, service users discuss impact on personal perceptions of self,

social stigmatisation and feelings of security. An awareness of the importance of personal aspects in the service providers appears to be lacking. Discussion of “successful outcomes” for service providers, while considering the individual nature of each user, revolve around physical outcomes and mobility, rather than being based on the explicit priorities of the user. While this paper intended to address technical aspects of prosthetic provision, they also revealed the often overlooked connection between physical and psychological meanings of prosthesis use for the prosthesis users and the potential impact that this may have on patient experience.

Several studies have commented on the negative impact that discrepant expectations and experience can have on patient satisfaction. In such discussions, the patient-prosthetist relationship is analysed as to the role that it may play in such perceptions (Liu et al., 2010; Nielsen, 1991; Pezzin et al., 2004; Sjö Dahl et al., 2004). Further investigation of the views of the patient and the prosthetist and other health professionals is warranted. Nielsen (1991) in particular noted that patients would welcome clarification of the role of the prosthetist and an increase in patient involvement. Patients report that a lack of relevant information hampers their ability to contribute to the decision-making process and thereby means that relatively greater amounts of control are apportioned to the prosthetist or medical staff (Liu et al., 2010; Sjö Dahl et al., 2004). This results in patients having to place “blind trust” in the professional whereas the patients would prefer a partnership approach to decision making, treatment planning and rehabilitation. Pezzin and partners (2004) reported that while a large majority of their large sample were satisfied with their prosthetic device, they rated their prosthetist less favourably. While the technical skills of the prosthetists were acceptable, their interpersonal skills and concern for the well-being of the individual were rated less highly. Communication skills (rated in terms of questions regarding time taken with patient, discussion of relevant issues and quality of explanations) were highlighted as being lacking for some. Further analysis of the impact of patients’ perceptions of the prosthetists on

experience of limb loss and prosthesis use on a personal level would be beneficial. A further study investigated patients' perception of care with regards to their expectations of the care process and expressed satisfaction (Van Der Linde et al., 2007). This study showed an inconsistency between what the patients expected from the clinical team and what they received particularly in terms of communication of information and aspects of impact of prosthesis use. This finding is reflected by Schaffalitzky and associates (2009) who ascertained a perceived lack of involvement of prosthesis users in the prosthetic choice process and a discrepancy of priorities between patients and prosthetic staff. This study particularly emphasises the need to consider the patient not as a passive user of a prosthetic device but as an integral part of the decision process, as "consumers" whose opinions and priorities should be central to the prescription process. The discrepancy identified here again underlines the need for further exploration of the experiences of both the patient and the practitioner in order to understand the nature and source of these discrepant views in an area which is, as yet, under-researched.

Murray (2013) investigated aspects of communication and understanding between patients and prosthetists from the patients' perspective. Through analysis of online discussion posts several areas of patient concern were identified. Patients appear to have a variety of expectations coming into the rehabilitation process in terms of the role that they and the prosthetist will have. In some cases the passive participant role with the prosthetist as expert is evident particularly in the early stages of rehabilitation. This can raise problems for the patient as they find it difficult to accept that the prosthetist, as someone who has no personal experience of limb loss and prosthesis use, can fully appreciate their concerns. Patients express concerns that they seem to be expected to engage in the process but often feel unable to communicate their views either through lack of confidence in their knowledge or lack of an appropriate relationship with the prosthetist. In some cases patients felt that the prosthetists were unwilling to participate in a collaborative relationship which they perceived

as an unwillingness on the part of the prosthetists to accept the patients' role in the process as being as valid as their role as "expert". The patients detail experiences which suggest a disparity between what they expect the prosthetists should be able to provide and the way in which this should be achieved versus their perception of the actual service delivered. The patient perception is that prosthetists fail, in some cases, to understand their needs as individuals. Participants discuss the need to foster a constructive and communicative relationship with the prosthetist as a means to tackle difficult situations or dissatisfaction, however this is not always translated in experience with more negative relationships being reported.

Murray (2013) highlights areas of concern and importance within the area of communication between the patient and the prosthetist as perceived by the patients. The difficulties raised by a discrepant understanding or expectation between the two parties within this partnership suggest a potential lack of patient-centred model and could lead to continued problems for patients in some cases. Murray (2013) offers an insight into such issues from a patient perspective. However, a focus on the patient-practitioner interaction and a fuller understanding of the prosthetists perspective on such issues is needed in order to identify and understand particular aspects of this communication which could be targeted for improvement. This additional perspective will be provided by the current study.

Chapter Summary

This literature review shows a variety of studies concerned with the assessment and prediction of potentially contributory variables to the experience of limb loss and prosthesis use. However these studies lack a full appreciation of either the understanding that an individual has of this experience or the personal meaning that they extract from it. Where the experience of individuals who have lost a limb has been investigated there has been varying focus on aspects such as the use of a prosthetic device, coping strategies utilised and

the early reaction to amputation (Gallagher & MacLachlan, 2001; Liu et al., 2010; Murray, 2004; Saradjian et al., 2008). However studies concerned with the overall lived experience of this group are limited (Hamill et al., 2010; Senra et al., 2012). Similarly studies concerned with the prosthetists' perspective of this experience are limited to the measurement of technological success or service related aspects with no studies providing comparison of their understanding of the individuals' experience (Mortimer et al., 2002; Mortimer et al., 2004; Schaffalitzky et al., 2011). A fuller understanding from an idiographic perspective requires the use of qualitative methodologies. Through such means it is possible to understand how the psychological and social variants of experience are understood by these individuals and the impact that they are likely to have on their rehabilitation and adjustment to amputation. The current study intends to address this by attempting to gain a subjective understanding of the complete lived experience of lower limb amputation from the beginning of the process, through clinical rehabilitation and prosthesis prescription and including long term impact on life.

The perception that the prosthetist has of the individuals' experience of amputation has the potential to impact not only on their clinical decisions but to have ramification for the patients' rehabilitation. Having a shared understanding in such a personally relevant area as prosthesis prescription is vital in order to ensure that the individual's needs are being met. Literature surrounding the area of patient-practitioner communication in other healthcare situations underlines the importance of this shared understanding in achieving mutually acceptable outcomes of a health based interaction or process (Hordern & Street, 2007a; Hordern & Street, 2007b; Ononeze et al., 2006; Ostlie et al., 2007). While this has been considered in the area of prosthetics from a technical or practical viewpoint (Mortimer et al., 2004; Schaffalitzky et al., 2011), the overall understanding of the experience of limb loss and prosthesis use from the prosthetists' perspective has not yet been investigated. This study intends to remedy this by gaining a novel, subjective understanding of the experience of limb

loss and prosthesis uses from the prosthetists' perspective. Finally, the experience of both the individuals with lower limb loss and the prosthetists will be compared in order to provide a fuller understanding from each perspective and the impact that each may have on the other.

Chapter 3: Methodology

The current aims to provide an understanding of the perceptions and understanding of amputation, prosthesis use and rehabilitation from an idiographic angle of both prosthetists and individuals who have lost a limb. Interpretative Phenomenological Analysis (IPA) has been chosen in order to answer the research question in as rich and detailed a way as possible, allowing a specific focus on the experiences of the participants while at the same time allowing for shared experiences to be discovered. This chapter details the rationale used in the selection of this methodology followed by an account of the research procedures utilised in the generation of the data for this study.

Phenomenological Psychology

Phenomenology, originating in the early 20th century, is the philosophical study of experience, the root of which is to come to an understanding of what living is “like” with reference to specific experiences. This has been defined as “*the study of human experience and the way in which things are perceived as they appear to consciousness*” (Langdrige, 2007, p. 10). Essentially, phenomenology is concerned with the lived experiences of individuals, how they perceive their world and their experiences and the meaning that they attribute to these experiences in the process. Through the development of research paradigms based on the central components of this philosophy, phenomenological psychology aims to provide an insight into individual experiences and a person’s life world. Giorgi and Giorgi (2008) further clarify this aim as being “*to capture as closely as possible the way in which the phenomenon is experienced within the context in which the experience takes place*” (2008, p.28). Phenomenological research in its classic form has been argued to consist of four key characteristics: rigorous description, phenomenological reductions, exploration of the intentional relationships between persons and situation, and the search for the essences of meanings in human experiences (Giorgi, 1989, as cited in Finlay, 2009).

While this core framework is adhered to strictly by some methods of phenomenological investigation, variations and deviations have been developed over time which offer alternative methodologies. Much of this variation centres on the concept of phenomenological reduction and proffers a split movement between transcendental and existential phenomenology. Proponents of early phenomenological thinking support the view of Husserl who believed that in order to gain an understanding of experience, we must “bracket off” our own perceptions and ideas regarding a phenomenon or experience (Smith, Flowers, & Larkin, 2009). In translating this to a research perspective, those who follow a Husserlian approach strive to introduce a process of reduction in which they attempt to remove all influence of their own experience and render themselves as neutral as possible (Finlay, 2009). In doing, so they adhere to a transcendental approach in which researchers attempt to step out of their own experience and view the experiences of others from this outside position, entirely unhindered by their own preconceptions (Langdrige, 2007).

In contrast to this are those who support an existential approach such as those of Heidegger and Merleau-Ponty (see Smith et al., 2009). This alternative view purports that reduction of one’s experiences and beliefs is neither possible nor necessary in attempting to make sense of others’ experiences. Existential phenomenologists believe that we exist in the context of the world and that as such our experience of the world is embodied. Heidegger used the term “Dasein” to describe our state of “there being” or “being in the world” and suggested that we can only interpret the world through our subjective experience of this state (Smith et al., 2009). In applying these existential components to phenomenological research, researchers are encouraged not to “bracket off” their own experiences but rather to acknowledge them reflexively and to recognise the central role of the researcher in the process of analysis and understanding. In these cases researchers apply *“critical self-awareness of their own subjectivity, vested interests, predilections and assumptions and to be conscious of how these might impact on the research process and findings”* (Finlay, 2008,

p.17). Such existential principles are applied in the use of Interpretative Phenomenological Analysis (IPA) which is used in this study.

Interpretative Phenomenological Analysis

Interpretative Phenomenological Analysis (IPA) is based on phenomenological principles developed for psychological research by Jonathon Smith (Smith, 1996; Smith, Flowers, & Osborn, 1997; Smith et al., 2009). As defined by Smith and Osborn (2008) “*The aim of interpretative phenomenological analysis (IPA) is to explore in detail how participants are making sense of their personal and social world, and the main currency for an IPA study is the meanings particular experiences, events states hold for participants*” (p.53). IPA aims to provide a personal perspective of an experience as opposed to an objective definition of an experience. The generation of an understanding and exploration of the meanings which an individual assigns to an experience are central to IPA. However, it is also recognised as a dynamic process in which the researcher has an active role in interpreting the meanings that this experience holds for an individual. This interpretative component and recognition of the researcher in the analytical process is central to the application of IPA.

Although initially developed for use in health psychology research where it remains commonly applied, IPA has been successfully transferred to a variety of other areas such as social and clinical psychology (Reid, Flowers, & Larkin, 2005). In recent years there has been a marked increase in its use as indicated by a rise in the number empirical peer reviewed studies using the methodology (Reid et al., 2005; Smith, 2011). IPA is not limited to providing a description of the individuals’ experience but offers an interpretation of its meaning to the individual and recognises the influence of social, historical and contextual influences on this understanding (Eatough & Smith, 2008). Similarly, the additional level of interpretation afforded by IPA allows an exploration of the participants’ cognitions in

relation to their experiences and the meanings that they extract from these. This affords the researcher a more thorough understanding than many other methodologies would allow (Reid et al., 2005).

With its roots firmly placed in phenomenology, focusing attention on the individual's lived experience; IPA also integrates aspects of hermeneutics and idiography in its theory and application. IPA displays an existential viewpoint in that it is argued that neither the researcher's nor the participant's personal experiences can be "bracketed" in their interpretation of the studied phenomenon. Rather than trying to remove all influence of such previous experience, they are instead recognised and reflected upon in the analysis process. In IPA there are two layers of interpretation present. This level of interpretation is referred to as a *double hermeneutic* and is a defining characteristic in the use of IPA (Smith et al., 2009). This process is described in terms of "*the participants trying to make sense of their world; the researcher is trying to make sense of the participants trying to make sense of their world*" (Smith & Osborn, 2008).

Similarly, IPA is committed to the idiographic nature of analysis, entailing a focus on the individualistic nature of the experience and its interpretation. In this way it can be argued that no two individuals will have the same understanding of a phenomenon as explained by Finlay (2008) "*each person will perceive the same phenomenon in a different way, each bringing to bear his or her lived experience, specific understandings and historical background*" (p.107). While this allows for the specific analysis of individual experiences including its application in case study analysis, more often the shared phenomenological experiences of participants are considered on an individual basis followed by patterns across these cases (Smith, 2011). In this way, not only are particular experiences of individuals considered but also the shared and divergent experiences therein which may lead to a greater understanding of this specific phenomenon. A successful IPA study is thought to present three levels of achievement: it should be interpretative, transparent and plausible (Reid et al.,

2005). In its interpretative nature the results are presented as a subjective understanding of a phenomenon as garnered by a skilled researcher. In its transparency, the results should be clearly grounded in the data in a bottom up analysis. Finally in its plausibility, the results should be clearly understood by the reader, leaving them with a sense of a true understanding of the phenomenon being presented.

Previously, IPA has been used with great success to investigate the personal experience of a variety of complicated health areas including chronic fatigue syndrome (Dickson, Knussen, & Flowers, 2008), irritable bowel syndrome (Schneider & Fletcher, 2008) and stroke (Murray & Harrison, 2004). In addition it has also been used to consider aspects of health professional experience (Carradice, Shankland, & Beail, 2002). Moreover, IPA has also been used in the research of amputation and the use of prosthetic devices (Murray, 2004; Murray, 2005; Murray, 2008; Murray, 2009; Saradjian et al., 2008; Sjö Dahl et al., 2004). This combination of the phenomenological focus on lived experience of the individual, the ability to interpret the experiences taking into consideration contextual factors and the focus on a particular shared event lead to IPA being selected as an ideal methodology for addressing the research question of this study.

Study Design

As IPA is concerned with the individual's experience of a particular event, it is important to allow them to share their story in the way which is most meaningful to them. While the participants have been recruited as they all share a particular experience, it is the individuals' own meaning and understanding of this experience that the study intended to uncover. The most commonly used method in IPA studies for eliciting participants' understandings of their experiences is that of semi-structured interviews. Semi-structured interviews are a flexible method of data gathering, allowing interaction between researcher and participants to flow in a reasonable naturalistic way that encourages the participant to tell his or her own

story in their own way. They therefore allow for a meaningful discussion between interviewer and interviewee, enabling the participant to lead the conversation while at the same time allowing the researcher to manage the discussion when needed. Semi-structured interviews thus provided a method of data collection that was especially appropriate for the present study.

Forms of Interview.

Interviews can of course be conducted in a range of ways. While, traditionally, much qualitative research has relied on the use of face-to face interviews, more recently researchers have made increasing use of the possibilities afforded by virtual media for data collection. Traditional face to face interviews can be conducted in a controlled time frame and do not rely on access to or ability to use a computer (Meho, 2006). In addition, face to face interviews allow the analysis of nonverbal communication such as body language, voice inflection, pauses, facial expressions (James & Busher, 2009). There has, however, been an increase in qualitative research in the use of internet based interview techniques – also known as Computer Mediated Communication (CMC) or Internet Mediated Research (IMR) (Meho, 2006; Murray & Sixsmith, 1998) as access to technology becomes more wide spread. There are a number of positive reasons for using email interviews in research and particularly in a potentially diverse group such as those living with amputation. Email interviews allows inclusion of participants over a much wider geographical spread and allows contact to be made with larger numbers in a much shorter space of time and much less cost (Meho, 2006; Murray & Sixsmith, 1998). This method also allows the inclusion of participants who otherwise may be excluded from traditional interviews whether due to an inability to travel or a personal difficulty with such face to face encounters (Egan, Chenoweth, & McAuliffe, 2006; Meho, 2006). This may particularly be the case in such research involving disfiguring or disabling disorders such as amputation (Egan et al., 2006; Murray, 2004; Murray, 2005; Murray, 2009). It has also been suggested that the use of

email interviews may encourage more candid honest responses from individuals when discussing difficult or particularly personal issues as their anonymity is further protected and the researcher is hidden (Egan et al., 2006; N. James & Busher, 2009). Further removal of the interviewer effect eliminates the possibility that the participant may be influenced by either verbal or non-verbal cues (Meho, 2006). In addition, the use of email interviews has been reported to encourage a more dynamic involvement of the participant in the process as they feel more able to question the interviewer and have more time to raise their own concerns or give their opinion (Egan et al., 2006; Evans, Elford, & Wiggins, 2008). A further benefit is a lack of time limit on the interview. This means that the both the interviewer and the participant have time to think through their responses before sending giving more considered answers and questions rather than simply what can be achieved in the allotted time (Egan et al., 2006; Evans et al., 2008). From the researchers perspective the use of email interviews also removes the time and cost involved in transcription of interviews and the data is already be in an electronic word format (Meho, 2006).

For the present study, participants were offered their choice of three options for interview: phone call, face to face or email. Arrangements were made as was appropriate to the participant. Each of these different forms of interviewing have varying benefits and drawbacks however each was considered to be suitable for use in an IPA study. Telephone interviews were also introduced to allow for the greatest flexibility for participants, particularly in cases where individuals were geographically removed, where email contact was not appropriate or where mobility was limited. Combining multiple data gathering methods have been used to great effect within the field of amputation research and was thought to be highly successful as a research technique (Murray, 2004; Murray, 2005; Murray, 2009).

Ethical considerations

Ethical approval for the current research was granted by the Queen Margaret University ethics committee and due consideration to the ethical guidelines of the British Psychological Society (British Psychological Society, 2009) was given at all times. The BPS ethics code is based on the four key principles of respect, competence, responsibility and integrity. This translates to a practice which ensures respect for participants at all times, ensured confidentiality and a protection of the participants within the study. The informed consent of all participants should be sought which also relies upon the provision of sufficient information to allow the participants to feel confident in their decision. Additionally, participants must feel comfortable within the research environment and be assured of their ability to withdraw from the study at any time. The researcher has a responsibility to ensure that no harm befalls the participant as a result of the study. In this case this included the potential for psychological distress at discussing a potentially sensitive subject. As such the researcher's competence is tested in their ability to recognise any signs of distress and act accordingly. This includes a debriefing session in order to assess any such effects. The researcher has a responsibility to maintain the anonymity of all participants and to ensure that all data is held in a secure manner in accordance with the stipulations of the governing ethics board.

Additional ethical guidelines exist for the use of online methods in research (British Psychological Society, 2013). These guidelines are intended to complement the standard practice guidelines already in place but with a specific tailored set of outcomes for Internet Mediated Research (IMR). In this case the aspects considered to be most relevant relate to the verification of identity of participants, the level of control (or lack of) over the participation process, the right to withdraw and the protection of participants and their data. The verification of identity may be considered to be difficult in some instances of IMR such as blog or chat room data. However this is not considered to be such a concern with email

interviews where email addresses can be verified and traced to a reliable and secure source. Ensuring a level of control and right to withdraw is clear to the participant may be more complicated. In instances where a participant has decided to withdraw from a study they may choose simply not to respond to the researcher's emails. This may result in an unclear withdrawal and therefore a continued and unwanted contact from the researcher. In IMR studies and in particular the use of email studies, the protection of data is imperative. Email interviews should be treated in the same way as any other interview transcript, anonymised and stored in a secure location ensuring the continued protection of the participant.

The following sections detail the specific steps taken within this study to ensure ethical practice throughout this study. These were considered in such a way so as to ensure the same ethical rigour in both online and offline data collection.

Informed Consent

All participants were provided with information sheets (either in printed or electronic form) and given the opportunity to ask any questions of the researcher prior to taking part. Consent forms were issued and collected before data collection began (see appendix for examples)

Anonymity and Confidentiality

All transcripts were anonymised with the use of initials and removal of all identifying features. Email interviews were transferred to word document files, similarly anonymised, and the original email trail deleted from account.

Right to withdraw

All participants were assured of their right to withdraw from the study at any time and their understanding of this concept was confirmed prior to commencing the interview. In the case of email interviews, the researcher explicitly confirmed the participant's willingness to continue before the next email was sent. In cases where a reply was not forthcoming from

an email, a maximum of two email reminders were sent over the course of two weeks before withdrawal was assumed and contact halted.

Participant safety

A minimum age for participation was set at 18 years old to ensure an adult pool of participants. Despite this, an awareness of the potential for vulnerability within the sample was maintained particularly with reference to the individuals discussing their amputation which may have caused distress. A continued vigilance for potential signs of distress was maintained at all times and close contact with supervisors ensured an appropriate course of action should anything untoward occur or advice be required.

Debriefing

All interviews ended with a debrief session in which the purpose of the study was reiterated and any further concerns or questions could be addressed. In addition all participants were given details of supervisor as well as further university contact should any questions arise which they wished to direct elsewhere rather than directly to the researcher.

Participant recruitment

The intention of IPA in a comparison study is the “*exploration of one phenomenon from multiple perspectives*” (Reid et al., 2005). In maintaining this focus demographic issues such as age, gender, reason for amputation are not considered to be necessary constraints in participant recruitment. Although it could be argued that such individual aspects may lead to differences in experiences, such differences are an integral part of the understanding of experience in an IPA study. For this reason the representativeness of the sample is not considered to be a guiding factor. Rather purposive sampling is used to obtain a group of participants who share the experience of the research phenomenon, in this case the experience of limb loss and prosthesis use (Smith & Osborn, 2008). While IPA does not dictate a particular ideal number of participants, its dedication to an idiographic approach

does necessitate small sample sizes. The level of in-depth, case by case analysis required for a successful IPA study limit the possibility to adequately cope with large numbers of participants. Similarly the desire to gain a rich insight into the experiences of each participant is a complicated and time consuming procedure which can only realistically be performed to a high standard on a small number of participants at one time. As summarised by Smith and Osborn (2008), IPA researchers are inevitably trading breadth for depth in their analysis. The nature of the intentions of IPA to make claims of the understanding of a particular group, on a particular phenomenon rather than to try and make any general claims on a topic confirms the need for a small and purposively selected sample. Recent review of peer reviewed IPA literature reveals a variation in sample size from 1 to 42 with an average per group of 15 participants (Brocki & Wearden, 2006; Reid et al., 2005) suggesting that this was an appropriate target sample for the current study.

Group 1: Individuals living with limb loss

Participants in this group were recruited via two support charities: The Murray Foundation and Port-ER. The Murray Foundation is an Edinburgh based charity offering peer support and practical advice to new and established amputees. Port-ER (Prosthetics, Orthotics and Rehabilitation Technology: Education and Research) is primarily involved with providing information and support to new amputees but also providing funding for research within the field. Port-ER is based within the prosthetics out patients department within Exeter Mobility Centre and is directly involved in providing patient information leaflets which are written in conjunction with health care staff. With the consent of both of the organisations, participants were recruited via each charity using printed flyers distributed in charity office spaces in both Exeter and Edinburgh as well as patient information areas situated within the outpatient department of Exeter Mobility Centre (see appendix) In addition, the invitation flyer was printed in the newsletter of The Murray Foundation which has a readership of approximately 1400 individuals with amputation and prosthetists across

the UK. Prospective participants were asked to email or phone the researcher in order to register their interest. They were then assessed according to the following inclusion criteria for the study: unilateral, lower limb amputation, minimum age 18 and surgical amputation rather than congenital missing limb (although elective amputation of a congenitally deformed limb was accepted as the key aspect being discussed was that of amputation of a limb). If these criteria were met interview arrangements were made. Participants were to be excluded if the amputation had occurred less than 6 months previously as research suggests a peak in the incidence of psychological problems, particularly anxiety and depression, during this initial timeframe (Price & Fisher, 2002). In this case however no such candidates volunteered.

Sixteen self-selecting individuals living with unilateral, lower limb amputation participated in the study. Participants ranged from 32-86 years of age with an average age of 60.5 years. Time since amputation ranged from 18 months to 64 years with the average length of time being 14 years. Reasons for amputation included peripheral vascular disease, congenital abnormality, cancer, diabetes and trauma (see table 1).

Table 1: Demographic data of individuals living with amputation

Participant	Gender	Age	Reason for amputation	Level of amputation	Time since amputation	Interview type
Penny	Female	57	Cancer	Right transtibial	12 years	Telephone
Tim	Male	55	Trauma	Right transtibial	15 years	Telephone
William	Male	71	Elective	Right Transtibial	4 years	Telephone
Neil	Male	62	Cancer	Right Hemi pelvic	15 years	Face to face
Gayle	Female	55	Elective	Right Transtibial	17 years	Face to face

Andy	Male	66	Vascular disease	Right Transtibial	6 years	Face to face
Craig	Male	81	Trauma	Right Transtibial	64 years	Face to face
Patrick	Male	81	Trauma	Right Transtibial	63 years	Telephone
Danny	Male	65	Ulceration	Left Transtibial	5 years	Face to face
Sam	Male	33	Cancer	Right Transfemoral	2 years	Face to face
Stuart	Male	66	Vascular disease	Left Transfemoral	1 year	Face to face
Holly	Female	49	Trauma	Right Transtibial	8 years	Face to face
Jim	Male	65	Vascular disease	Left Transtibial	1.5 years	Face to face
Tom	Male	65	Vascular disease	Left Transtibial	4 years	Telephone
Sean	Male	39	Trauma	Right Transtibial	5 years	Email
Gareth	Male	58	Vascular disease	Right transtibial	3 years	Face to face

Group 2: Prosthetists

Thirteen self-selecting prosthetists participated in this study, with 6 males and 7 females. All prosthetists were currently employed in clinical positions. They ranged in qualification time from 3 -30 years. Participants for this group were recruited via invitation phone calls and emails to prosthetic departments in Scotland. Initial contact was made with the lead prosthetist at WestMARC rehabilitation and mobility centre (Glasgow), Astley Ainslie Hospital (Edinburgh) and the National Centre for Prosthetics and Orthotics (Glasgow). Contact was also initiated at several other centres throughout the UK however time restraints of the project prevented these from being included in the study. The lead prosthetist agreed

to pass on invitations to prosthetists within the department in the form of invitation flyer and emails (see appendix). Interested parties were invited to contact the researcher at their convenience to allow interview arrangements to be made. In some cases the lead prosthetist acted as contact throughout allowing for arrangements to be made on a group rather than individual level. Inclusion criteria for this group detailed the necessity of being a fully qualified, currently employed, prosthetist, registered with the Health Professions Council (HPC) (see table 2).

Table 2: Demographic data of prosthetists

Participant	Gender	Interview type
Steve	Male	Face to face
Adam	Male	Email
Mel	Female	Email
Chris	Male	Face to face
Mike	Male	Face to face
John	Male	Face to face
Anne	Female	Email
Nicola	Female	Face to face
Eve	Female	Face to face
James	Male	Face to face
Angie	Female	Face to face
Kate	Female	Face to face
Jenny	Female	Email

Data collection

Devising interview schedule

In using a semi-structured interview, an interview schedule was prepared however this was merely used as a guide for the interviewer should the interview appear to stall or halt at any stage (see appendix). The interview schedule was devised through careful consideration of the research question in that it was intended to gain a subjective knowledge of the participants' experience. Individuals living with amputation were asked to reflect on their experience of limb loss and prosthesis use. Prosthetists were asked to reflect on their perceptions of limb loss and prosthesis use as gained in their professional role. Participants were first asked a general question asking them to share with the interviewer their experience. All subsequent questions were then used to clarify or expand on a point raised by the participant. This allowed each participant to give a true reflection of the aspects of the experience that was most salient to them as opposed to a prescribed point of view dictated by the interviewer. Particular points of interest or prompts were used in such instances where the interviewee appeared to need encouragement. These prompts were guided by both a review of the literature in the area and the interviewer's specific knowledge of the subject perhaps taking in to account previous interviews and interpretations up until this point. The participants were encouraged throughout the interview to share any aspects of their experience that they felt were important. The interviewer maintained a conscious awareness of allowing participants to explore any avenue they wished particularly if this was an area which had not been previously highlighted either in the literature or previous interviews.

Face to Face interviews

Participants were informed that the interview would last approximately one hour and that they were free to stop at any time. In practice the interviews lasted between 60-90 minutes with two lasting up to 120 minutes. All interviews were recorded on a digital voice recorder in agreement with the participant. With face to face interviews nonverbal communication

cues are present. In these instances annotations were made on the transcripts from notes taken during and after the interview itself (e.g. *sigh, points to amputated leg, shrugs, shakes head*).

Group 1: Individuals living with limb loss

In total 10 individuals with amputation chose face to face interviews. Interviews were conducted at a time and place that was mutually convenient. Due to physical limitations and transport difficulties of 8 of the individuals with amputation, it was agreed that the researcher would visit them at home. On two other occasions the interview was held in a meeting room at Queen Margaret University and in a local tea room as this was preferable to the participant.

Group 2: Prosthetists

Nine prosthetists elected to take part in a face to face interview. Prosthetist interviews were conducted over the course of two separate days, one at Astley Ainslie Hospital (Edinburgh) and one at the National Centre for Prosthetics and Orthotics (Glasgow) where all interested participants were interviewed in succession. This was at the request of the prosthetists in order to minimise disruption to their time.

Telephone interviews

Telephone interviews were conducted via a prearranged phone call where the researcher contacted the participant on their provided phone number. The phone call was recorded via telephone adapter on a digital voice recorder in full agreement with the participant. Participants were informed that the phone call would last up to 60 minutes and that they were free to stop at any time. The majority of interviews were completed within a 45-60 minute window with only two lasting up to 80 minutes.

Group 1: Individuals living with limb loss

Four individuals chose to participate via telephone interview. This was at the preference of the participant who deemed it more convenient due to geographical distance and time limitations. Several expresses a preference for telephone interview over email as email interview was thought to be too complicated and likely to take up more of their time overall.

Group 2: Prosthetists

None of the prosthetist group chose to participate via telephone interview. This was expressed as a preference to either meet face to face or to be able to participate in their own time via email.

Email interviews

These interviews began with general questions again regarding the history of the amputation and the overall experience. The participant's answers were then used to ask further questions in subsequent emails. Email interviews began with an overview of the study and an explanation of the procedure for conducting the interview. It was suggested that this was likely to involve four or five return emails with each asking different questions or for clarification or expansion on a previous point. On average each interview required four return emails ranging from two to eight and spanning a 15 day period. This variation in number was dependent on need for additional questions and willingness of the participant to continue.

Group 1: Individuals living with limb loss

Email interviews were only utilised by one individual. This participant lived a considerable distance from the researcher which made a face to face interview impractical. In addition, this participant felt that email interviews would be easier for him to respond to as he would be able to do it at his own pace and around his other commitments.

Group 2: Prosthetists

Email interviews were chosen as the most preferable method of participation by four prosthetists all of whom agreed that this was the less intrusive method of participation given their work schedules.

Transcription

Face to face and telephone interviews were transcribed verbatim from the digital recording. In all cases as much detail as possible was transcribed with any instances of unclear diction being noted in brackets and a best guess at the missing word being indicated in italics such as (*appliances?*). Similarly any relevant non-verbal cues or actions were also noted in square brackets such as [pause, sigh, laugh, becomes upset, points to device] as this was considered important for the analysis process in reminding the researcher of the participant's mood and reaction at any point. Any information which has been removed by the researcher for confidentiality purposes has been replaced by an explanatory note in double brackets for example ((prosthetist's name)). Similarly any relevant contextual information was inserted in double brackets with italics removed, such as ((while discussing limb fitting centre)). Where the transcript has been shortened by the researcher this is indicated using brackets and ellipses, indicated as (...). Repeated listening to the interviews during the transcription process was beneficial to the analysis process as the content became more familiar to the researcher. Email interviews were contained in a "paper trail" from participant to researcher and as such did not require transcribing. Each interview was copied into a word document to allow for continuous reading of one set of answers from a participant creating a transcript for each. Each transcript was then prepared for analysis with the addition of individual line numbers and left and right margins for annotations and note taking.

Analysis

There have been a variety of guidelines presented for using IPA. There is no prescribed 'method' for analysis of data as such allowing a degree of flexibility for the researcher to adapt the method to suit their own preferences and needs. The key component of the methodology is the maintenance of the phenomenological ideology of the method along with transparency and plausibility as discussed by Reid and colleagues (2005). Smith, Flowers and Larkin (2009) advocate the use of common practices such as the progression from the individual experience to that of the group and the consideration of descriptive factors leading to a more interpretative analysis. This project was based on those guidelines presented by Smith and colleagues (2009). Each interview was analysed individually to consider the specific experience of each participant followed by comparison both within and between groups. The dynamic nature of the IPA process means that this analysis process continues throughout the writing process. In the writing of this thesis, the continued thought process regarding the data as well as feedback from additional researchers and the personal reflection of the researcher led to the adjustment of themes and in some cases the removal of originally included data. This was done with due consideration of the key features of an IPA study, ensuring a focus on the individual experience, a high level of transparency and an awareness of plausibility at all times (Reid et al., 2005).

Initial analysis was conducted on the transcripts from group1, individuals living with limb loss. Firstly a transcript was read multiple times ensuring a focus on the participant and immersion in the data. This allows an overall mapping of content and structure as well as raising awareness of interview dynamics and areas of specific interest. The transcript was then reread, noting anything of particular interest in right margin focusing on description and content, highlighting key words, events and experiences. Further analysis of a more interpretative nature then looked for interpretative codes, creating emerging themes within the data. These themes were then gathered together in order to consider links and overlap

therein. Such clusters of emergent themes were highlighted with quotations from transcript. Within each identified theme, sub themes were also identified and illustrated accordingly. At the end of this stage of the process the transcript has been annotated and reduced to a series of “theme sheets” containing theme and sub theme headings and appropriate illustrative quotes from the data. Theme exploration was discontinued when it was felt that the level of analysis has reached saturation, that is when no more obvious points of interest were apparent. The relevance of the concept of saturation has been discussed at length with Smith and colleagues (2009) arguing against the appropriateness of such a constraint in an IPA study. They argue that given the cyclical nature of IPA, the analysis process could continue indefinitely, never reaching the point where no new interpretations can be made. However, in this case, such constraints were pragmatically applied when it was felt that the level of analysis had revealed the most relevant and prominent aspects of the experience in question.

This process of analysis was repeated on the remaining transcripts with any themes and sub themes being noted. This was done in consideration of the emergence of new themes from within the data but also with attention to those themes already identified within the first transcript. This level of intense analysis continued for six transcripts at which time it was considered that no further new themes were emerging and saturation had been reached. The remaining transcripts were then analysed on the basis of the identified themes and sub themes while at all time maintaining an awareness of the potential for new themes to emerge. In addition any negative cases, whereby an individual presented an alternative view to that of other participants or where a particular theme did not emerge, were considered. In some cases these resulted in the reanalysis of a particular decision to include a theme in the analysis altogether or to consider the meaning that was being drawn from it.

Following the analysis of each individual transcript, the theme and sub theme names were considered along with their relation to each other both within and across the transcripts.

This allowed for a set of master themes to be developed which was considered to represent the experience of the group as a whole and could be clearly identified through the selection of exemplifying quotes. For instance, this quote from Gayle was worked up into the initial theme “Positive peer support”:

I think it helps because it lets new amputees realise that there is life after hospital. This is not you for the rest of your life, stuck in a wheelchair, sitting at the side of your bed. You can get out and about. OK you may have to have modifications done to your car but you can still drive. This picture of normality and I think that's so important and knowing that there are other people around that you can speak to if you want to (Gayle, 605-609)

This was combined with other quotes and themes, for example this quote from Craig, initially coded into the theme “Positive peer comparison”:

I went into somebody in Cumbernauld one time and he was to go into hospital and they were going to take both his feet you know. And he said to me “will I be like you? Will I be able to dance? Will I be able to run?” but not everyone will be the same as you. Just cause you can do that doesn't mean other people will. (Craig, 524-527)

This was further considered with additional quotes such as this example from Sam, originally included in his theme of “Unique comparability”:

The thing more than anything that I would have liked was to meet somebody who was roughly ages with me and that or maybe even roughly ages with me who wasn't like over fifty (Sam, 1228-1230).

Together these data and further individual transcript themes were worked up to Social Comparison for the Individuals living with amputation group which became a sub theme of Social Identity which is presented in chapter 5, page 103. Further examples of the

development of sub themes and master themes from individual data can be found in appendix

This process was repeated for the prosthetist group resulting in the creation of master themes and subthemes which were representative of their experience. Provisional themes and sub-themes for both groups were then cross analysed in order to identify a common theoretical framework. In this way, themes were identified which were found in both groups. However, within the identification of these common themes, differences in the meaning and understanding that these held for each groups were apparent. Four common themes of personal identity, social identity, the prosthesis and communication form the basis of this study. Particular attention will be paid to the difference in understanding within these themes and the potential impact of this on experience and rehabilitation. These themes and the differences in understandings of prosthetists and individuals with limb loss are examined in detail in Chapters 4 to 7.

Chapter 4: Personal Identity

Introduction

A first theme for both prosthetists and for individuals living with limb loss related the impact of this experience on personal identity. Personal identity in this context can be defined and understood with reference to the psychological and philosophical writings of William James (W. James, 1890, as presented in Wozniak, 1999). James provides the distinction between “I” the subjective knower, and “me” that self which is objectively known. In simpler terms this can be understood in terms of “I” relating to the way in which an individual views themselves, from an internal, subjective perspective. The alternative self-view of “me” is understood in terms of how an individual considers themselves in relation to other people, contexts and how they consider themselves to be viewed or understood by others. Taking this explanation into account, the experiences shared here are discussed in terms of personal identity, the “I” perspective while Chapter 5 details social identity, the “me” perspective.

The renegotiation of personal identity following amputation, and the meaning which this holds differs somewhat between prosthetists and individuals who have lost a limb. Conceptualisations of personal identity, and of the particular priorities of both the individual and prosthetist, are influenced by previously held beliefs of amputation, disability and self. While the prosthetists hold their own perceptions about the identity of individuals post amputation, the individuals’ experiences reveal a different set of meanings and resultant understandings of their circumstances. Amputation often forces a reassessment of personal identity and a reclassification of priorities in order to negotiate adjustment to limb loss. This reassessment encountered by the individuals may not always be fully appreciated or understood by the prosthetists. In addition, the prosthetists are likely to hold their own preconceived ideas of the impact of amputation on identity which may, in turn, influence

their view of the experience from the individuals' perspectives or indeed their clinical decisions.

The second sub-theme to be discussed within this chapter is that of individual attitude and adjustment. This concept explores how an individual might come to accept their new reality and the potential influence that their attitude may have on the eventual outcome. Both prosthetists and individuals following amputation suggest that an individual's attitude and reaction to the newly presented situation of limb loss can have a dramatic effect on the success or failure of rehabilitation. Post-amputation participants expressed the opinion that a positive, active and personally responsible attitude was important in promoting successful adjustment and rehabilitation. The prosthetists in this study also expressed this sentiment. In this case however the level of responsibility placed on such attitudinal influence for successful rehabilitation was considerably higher than in the individuals' experience. An ability to adjust to a new reality and to reassess priorities was discussed as being fundamental to successful physical and psychological adjustment. Both groups discuss the impact of this individual attitude on adjustment but with differences in the level of personal volition and responsibility that this holds at the level of impact on rehabilitation.

Identity following amputation and impact of attitude on adjustment both lead on to the final sub-theme of this chapter, that of defining normality. Normality is a concept which is discussed by the majority of participants in some form and is often discussed in disability and physical difference literature. The question "what is normal anyway?" is asked by both post-amputation participants and prosthetists. Again, the post-amputation reality for many individuals forces a reconsideration of what the concept of normality means to them. In addition, the prosthetists' understanding of the concept of personal normality is vitally important in order to fully support individuals through their rehabilitation. The central theme of normality is not concerned with conforming to a uniform or comparable version of other people but to regain or maintain a sense of individual normality. For some this may

prioritise function over aesthetic appearance, put greater emphasis on a particular ability, allow for adjustment or compromise in one area over another. Regardless of the specific concerns of an individual, the unifying theme is that of maintaining or renewing a personal and unique normality: Get me back to “me”.

Prosthetists’ Experience

Identity following amputation

The way in which an individual classifies themselves following amputation is deemed by prosthetists as having an important influence on their rehabilitation. The categorisation of patients in terms of their personal acceptance or non-acceptance of their amputation was prevalent amongst the prosthetists with labels such as “disabled” or “non-disabled” being used to describe individuals. The implication made was that patients who think of themselves as being “disabled” or “invalid” are less likely to make a concerted effort with the rehabilitation programme. In addition they were thought of as being more likely to rely on others than to try to be self-sufficient while other individuals who do not categorise themselves in this way are more focused and determined to help themselves:

Other people will say, ‘Well, I’m now an amputee, I’m going to sit here in my wheelchair and let everybody do everything for me’. It can be family influences, their wife or their husband, just takes over and does everything for them. They are now treated as an invalid and they will be for the rest of their life and they just fall into that role; they are now helpless and they need somebody to do everything for them, other people are so determined that they are going to lead a normal life that they’ll do everything they can to do that. They will spurn help from partners and family because they want to be independent and really, I don’t know what the trigger is for these people to go from one extreme to the other but there’s definitely that category. (Chris 123-131)

The prosthetists' perception is that patients not only have a personal influence in the "role" which they play but also that distinct categories exist within their patient population. Once set, they view these characteristics as static within that individual rather than dynamic categories determined by personal, social or familial factors.

Similarly this classification was raised again in distinguishing between those patients who accept this identity label and those who do not. This is construed in negative terms suggesting that those who did classify themselves as "disabled" were less willing or able to facilitate their own rehabilitation and relied upon this disabled identity in order to justify their lack of physical activity:

you do get some people who don't like to say 'classified as disabled' because they don't think they are (...) Then you get the other people that feel they don't get enough support from maybe Disabled Living Allowance and Benefits because they think they're disabled and they can't work and the DLA think they can. (Kate 385-390)

By using the term "disabled" to describe oneself the individual is perceived as negating any overt attempt to achieve goals in positive rehabilitation or as being less active than those who did not like to use this term or categorisation for themselves. The implication from the prosthetist is that not only do patients classify themselves but that this will have wide reaching influence on their lives, their rehabilitation and further into their life in general, such as work patterns or expectations of benefits. In addition this categorisation is considered to be enduring, with the individual being perceived as maintaining the properties of this category over a long-term period.

Positive categorisation is also used by the prosthetists to identify individuals who have reached what they would deem a successful or satisfactory level of rehabilitation. While those who struggle to cope may be assumed to be self-categorising as "disabled", those individuals who are able to proudly present themselves to the world as a newly rehabilitated

individual living with amputation and are happy to display their prosthesis with little or no concern are deemed to be successfully rehabilitated:

so they're actually just saying: I've had an amputation. I've got a prosthetic leg. Here it is. (Kate 212)

This would appear to reflect on the prosthetists' own perceptions of what successful rehabilitation of self following amputation should entail and in turn reflects their clinical goals.

The perception of the prosthetists that such categories and personal identities exist gives an insight into their anticipation of how a patient will react to rehabilitation or the goals that they may have, based on the prosthetists' own categorisation of them. The change from able bodied to disabled, as identified by the prosthetists, reflects a personal view on disability and on the disabled population as a whole. "Disabled" or "invalid" are used to describe the patients who they feel are not achieving a standard of rehabilitation that they as professionals and also as individuals would be willing to accept. Similarly "accepting" or "adjusted" are terms used to describe individuals on the opposite end of the spectrum who are unwilling to be limited by their amputation and who are perceived by the prosthetists as having overcome this obstacle. The division of individuals into one of these two categories appears to be pervasive. The dualistic and static nature of this perception of identity and the assumed implications on rehabilitation and outcome reflects a potential for a differing understanding to that of the individuals. Such differing understanding offers a circumstance in which clinical practice and individual priorities may differ. The personal reaction to amputation of the patients and the impact that this may have on rehabilitation is similarly linked to the second sub-theme of individual attitude and adjustment.

Individual attitude and adjustment

In response to discussions about patients' adjustment and reactions to amputation, prosthetists' perceptions included a need for a positive personal attitude from the patients. They expressed the idea that amputation for the most part should be considered not as life-limiting but life-saving and that individuals had the opportunity to make the best of that situation. This extract describes what the prosthetist thinks is the typical mind-set and thought process of a patient who has lost his limb due to cancer:

'O.K. I've had to have my limb amputated. I've undergone the chemo. The chemo's not killed me. I'm in a good point just now. I'm recovering. I'm building my strength up. My hair's growing back. I'm getting my limb. I'm putting my life back on track' and they're just a lot more positive but a lot of them are just happy to be alive at that stage. (Mike 421-424)

This description shows, not only the perception that patients are grateful and relieved that they are alive but also that they themselves have personally influenced the outcome of their rehabilitation and have had a personal responsibility in achieving their goals. This sentiment that a patient's personal attitude has a positive impact on their rehabilitation and that, for the most part, they are able to incorporate that in to their personal identity is confirmed in several prosthetists' experiences. Individuals taking ownership of the situation and striving to not allow the amputation to interfere with their lives is an experience which the prosthetists shared:

some patients will be very proud of the fact that they had this event in their lives, whether it was an accident or something; that they've recovered from it, they've got this prosthesis and they are getting on with their lives. (Chris 121-123)

Here individuals who have a positive attitude are perceived as being more likely to achieve a higher level of adjustment following amputation and to successfully adapt to using

a prosthetic device. Interestingly, the inference is that the outcome of rehabilitation may be determined by the personal characteristics of the patients. It is suggested that personal attitude can be measured in a successful rehabilitation and that the influence of the patient's attitude on their own rehabilitation is fundamental:

Bottom line though, I think if someone has been quite positive and up-beat in the past, after amputation they often make a very good go of things. Naturally, most people relish the chance to get back to everything they did before, and health allowing, if they manage to do that, are naturally appreciative. (Anne, email 9-12)

In many cases the prosthetists felt that they could only take the patient so far in terms of achieving their goals but that the attitude of the patient was a defining factor in their rehabilitative success:

Occasionally patients blame the service, the prosthetist, the weather for everything not working for them whereas a change in their attitude may be the most beneficial factor. (Anne, email 49-51)

The level of responsibility for rehabilitation being placed on individual attitude indicates that prosthetists consider this to be a large contributing factor in the overall process. This perception should be considered with care as to the potential contribution of personal attitude and the influence that such views may have on clinical judgement of the prosthetists. Further discussion of this topic in relation to the expectations that both parties have of the rehabilitation system will be presented in Chapter 6: The Prosthesis.

Defining normality

In contending with an adjusted identity or renegotiation of personal meaning surrounding amputation, the priority of prosthetists is declared to be the return to a sense of pre-amputation normality for their patients. Normality is viewed as a personally unique state and

the prosthetists perceive themselves as having a key role in facilitating the restoration of this state:

Basically to return to what they would conceive as everyday life, normality for want of a better word and again, this is where it becomes a bit more difficult because it's individual (...) you won't make it perfect but you might make it a little bit easier. I don't know. It is quite tricky because it's really (...) As I said it's a personal thing because not every young person wants to go climbing mountains and not every old person just sits in front of the T.V. all day so it's very much an individual thing and you can't, you know, If there's one major thing that this job's taught me it's 'Never judge a book by its cover'. (Mike 567-579)

The individual needs of the patient are claimed to be at the forefront of the intentions of the prosthetists. That each person will have their own idea of “normal” relative to their own lives, expectations and priorities is claimed to have an impact on the prescription process. Many of the prosthetists expressed a dislike of using the term “normal” in terms of describing the ideal outcome for patients. The comparison between able bodied people as “normal” and the amputee population was something which they were keen to avoid. Rather, the use of “normal” was in relation to the patient’s desire to return to their previous state of activity. In relation to the ideal outcome for individuals and a return to “normality”, prosthetists reported the functional requirements of their patients as being priority over cosmetic appearance and declared their responsibility as professionals to meet these needs. The relationship between a sense of personal identity and functional ability was apparent when discussing what they perceived to be the priorities of patients:

there's the self-image thing, oddly less than you would think. Mainly it's about function and pain so people are saying: "I can't do what I used to do, I get more tired. My leg hurts and I have to stop" so I think it's about curtailment in their life that's the biggest issue as much as what it looks like. (Eve 8-11)

This prosthetist goes on to explain that, for a small group of individuals, the changes in their physical appearance are a real and important concern which may have a negative impact on their adjustment in both a personal and social sense. However she perceived this group to be the minority with functional limitations holding the key to what she considered to be a satisfactory rehabilitation. This experience is shared by other prosthetists where the patients' sense of self identity was considered to be integrated with certain functions and roles. The prosthetists recognised their key role in enabling the individuals to achieve these goals wherever possible and that for them this provides a sense of achievement in their role:

But you do get other patients maybe you've brought them in, you've changed their prescription in some way, you've improved their prosthesis in some way and they are now in positively reporting "this prosthetist will allow me to do X Y and Z that I couldn't do with my old prosthesis. I can now walk round the supermarket, I can now get down on all fours and play with my grandchildren" and all that type of thing so it can be quite positive. (Chris 49-53)

In addition to functional aspects of rehabilitation, aesthetic or cosmetic aspects of the prosthesis are also considered. Again, the term "normal" is difficult for prosthetists as they recognise that this will differ from patient to patient and that what they consider to be "normal" is central to their needs:

what you've got to remember is, there's a difference between you and I looking at that person as opposed to them looking down or looking at themselves in the mirror or looking down at their limb. You know that's a different view and it's their view that counts. It was never my view. My view doesn't matter. It's their view of themselves. (Steve 434-437)

Prioritising the patients' own view of themselves over that of the prosthetists acknowledges the role that the individual should play in the rehabilitation process. In terms of appearance and function, there appears to be a vast difference in terms of what will be

accepted as “normal”. This may entail having a prosthesis which has a cosmetic appearance which makes it indistinguishable from the non-amputated leg. In other cases, appearance may refer not to the actual prosthetic device but to the complete appearance and function of the individual while using the device:

I think it's just down to the individual; I think some people will be happy to walk about in a pair of shorts and something that looks clearly like an artificial limb , other people will just want it covered up and make it look as much like their normal one as best as possible.
(John 570-573)

The attention given to determining what the individual themselves is looking for and the function that they want the device to play in their lives in order to achieve this sense of personal normality is claimed to play a substantial part in an ideal clinical process. However, further discussion of the practical applications of these views in clinical practice suggests that such ideals are not always implemented, particularly in terms of determining which aspects of prosthesis use should be prioritised:

It's a standard question that and it's one where I do know that the prosthetist's perception may well be different from the patient's. My own take on it would be comfort has to come first. Once you've got comfort then you can look at function and or cosmesis. I'm not sure which of these would be rated most highly. (Steve 97-100)

In this case, despite assertions that recognition of the individuals' priorities for a return to a personally relevant normality, with whatever factors that entails, the prosthetist's own priorities for prescription are high on the agenda within clinical practice. The potential discrepancies between patient's and prosthetists' priorities in such cases are acknowledged, however the impact of these differences is not explicitly recognised. Developing a shared understanding of the individuals' needs for their devices is crucial in order to develop clinical practice in a more patient centred direction.

Individuals' Experience

Identity following amputation

As defined in the introduction of this chapter, conceptualisations of personal identity centre on the individuals' perceptions of themselves from an internal perspective, in the role of "I". This identification is often categorised by a definition of self that is heavily laden with descriptions of activity, function and personal roles. When asked "tell me about yourself" the responses feature, for the most part, descriptions of active roles, work and sporting hobbies; a recollection of a former self that has activity at the forefront. Even when the examples given of an active self are from many years previously, they still appear to influence the participant's current view of themselves. This perception of 'pre-amputation self' may or may not be relative to their post-amputation state but the way they see themselves is influenced by things they used to do or the ideal of what they would like to be doing. Who they are is very much defined by what they do or did prior to amputation.

Personal identity, as might be expected, incorporates historical representations as well as current ones. So someone who was active as a youth maintains that representation even if they were less active as an older adult. This recollection of previous activity and definitions of self often induces a state of melancholy, of reminiscing and of disappointing comparison with his current level of functioning:

Before I had my motorcycle accident, I ran for South Devon cross country, I boxed and played squash for Southend so I was a very active youth, playing rugby and stuff like that. So after the accident, I used to long for those days when I could run down a hill and jump from rock to rock and do all the things I used to do, I'd kind of dream about them. I missed them tremendously. (Tim 332-336)

The amputation is seen here to be preventing the participant from being the person that he wants to be. It is notable how he defines his previous life in terms relating to activity, function and vigour.

This experience of an initial reaction to amputation reveals the difficulties faced in trying to comprehend the changes required to make to self-identity:

when I came out of the shower I just sort of turned round and there was a big full length mirror and I just burst into tears and I was like 'Oh my God, how have I ended up like this?' (...) Aye, just seeing myself and no being able to...basically at that time cause I hadn't had a leg and I didn't know what I was going to be able to do and all I could see was me in a wheel chair and I was just like [sigh] 2 weeks ago I was playing football, working and today I'm sitting in like a war time hospital surrounding by old folk. (Sam 222-230)

In comparing past and current versions of himself this highlights the difficulties that he was having in reconciling his new reality and of adjusting to the changes in function and appearance that he is faced with. Similarly the comparison he draws with the "old men" suggests that he is no longer able to think of himself in the same way as he did before, that his previous young active self has been taken from him. While it could be argued that time since amputation may be influential in this adjustment to post-amputation identity it would appear that this only partially accounts for an individual's ability to generate their own sense of identity. While this case presents an initial reaction from a time immediately post amputation, individuals at the same point in the medical process report very different attitudes to their situation and to their levels of acceptance at this stage, indicating an early personal decision to react in a way which they felt was most helpful to their own adjustment:

The acceptance wasn't [pause] well I think it was, when you are in the wheelchair first of all, you just have to make a decision I think. I remember the first night afterwards, I had to call someone because I had to get up to get out of bed to the toilet and I thought, you have

to do this yourself if you want to keep your dignity and I think it was that decision that pushed me forward on it. (Gareth 153-157)

Similarly, issues such as age, reason for amputation and level of amputation may all influence the outcome in terms of an individual's ability to readjust their personal identity post amputation. It would appear that varying degrees of adjustment are seen in individuals with contributions from multiple factors, none of which can be definitively held accountable for adjustment to, or creation of, a new identity post amputation.

The functional benefits of using a prosthetic device and the role that this played in maintaining one's personal identity were central to the maintenance of personal identity. While losing part of one's body was perhaps initially more difficult to reconcile, it was the functional aspects of life and how to maintain this that mostly concerned participants. The concept of adjusting to functional differences and finding new solutions to difficulties was something of a key challenge:

It wasn't at all anything to do with losing a part of my body; it was partly losing my ability to do things. Emotionally, it wasn't depression or anything, it was just ups and downs a lot - that was occasionally when I found I couldn't do things that I wanted to do but then I worked out other ways of doing things or I found other things like the archery which I could do. So rather than a big dip, there were a lot of little ups and downs. (Neil 124-128)

The question of personal identity was raised by participants at various stages through their rehabilitation and life after amputation. As well as the initial readjustments followed by the assessment of priorities and negotiations of abilities there was also discussion of future self – who will I be? This comparison to their imagined future self played a similar role to the comparison to their past or ideal self. The majority for the participants expressed some thoughts and concerns for their future. While they may have had an idea or aspiration of life direction, for many a reassessment of this future self would be needed:

I start just thinking about daft things, well no daft things but like being in the swimming pool with my son, which I've no got obviously, or my daughter, and like things that I'll never be able to do, I mean I can go in a swimming pool but I'll never be able to walk you know, just daft things like that. Playing football with a son or a daughter, and when I'm thinking realistically I think I will be able to do that (...) I'll no be the same as I would have done before. (Sam 532-537)

The referral to “daft things” he thinks about and whether he will be able to achieve these things offers an interesting insight. While the activities he refers to may be considered everyday activities in themselves, it is the larger role of being a father that concerns him with the examples he gives being central to what he thinks of a typical father requirement. This concern with future self again reflects the importance of fulfilling an active or functional identity.

When issues of physical limitations were raised by participants, differing attitudes with regards to open acceptance and categorisation of self on this basis were evident. While most were happy to discuss their changes in activity and adjustment to their new life situation, these same individuals presented some issues with being able to be open about this new personal identity. In particular, concerns arose in terms of admitting to needing additional help and support or to being publically open and categorised by their amputation. Amputation brings about a reassessment of self-categorisation. For some they consider themselves to be “an amputee”, or an “individual living with amputation”, for others this categorisation is neither helpful nor even a matter of interest. In some cases, the identity of “amputee” was difficult to accept. For others these changes were more readily accepted and often this aided their sense of adjustment and acceptance of their own post-amputation identity. The idea that definition of self should not be based on this medically-required procedure was evident in many individuals:

Obviously I am disabled, but i [sic] don't view myself in that way. Also I'd never refer to myself as "an amputee". The fact that I've had an amputation doesn't define who I am. I'm the same person i [sic] was before the accident, i [sic] just happen to have an amputation. That's why I'm [sic] not really interested in joining any amputee groups. (Sean, email 156-160)

Maintaining a personal identity post amputation that allows for a preservation of the defining aspects of a pre-amputation self was highlighted as important. Having had an amputation does not make him a different person per se, simply the same person with a different set of needs and abilities. His desire to distance himself from any categorisation or membership of a particularly labelled group suggests the perception that such a labelled identity would be devaluing, which he actively refutes.

In other cases identifying with the label of “amputee” was less problematic. Allowing adjustments to be made in order to accommodate changes in ability that have been caused through amputation meant that this individual felt better able to continue to fulfil the role of ‘self’ as she defines it regardless of any particular label. Placing less importance on the particular terminology used suggests a level of disregard for such things:

An amputee is an amputee. What is left of your leg is a stump, it's not a residual limb - you are now either transtibial or transfemoral. [pause] I'm an amputee with a peg leg, you are not going to change that. (Gayle 167-169)

By discussing her limb loss and use of prosthetic device in such matter of fact terms she demonstrates the ease with which she now identifies herself. This level of acceptance may take time after amputation as the new reality of the situation presents itself and the necessary adjustments are made.

The integration of this reassessment of self-identity into everyday life and the impact that it may have on an individual's perception of them-self is exemplified by the use of a "blue badge" for disabled parking spaces. One individual felt she had to justify being "disabled enough" to deserve one and confessed to feeling awkward or even guilty at using one even though, by her own admission, there were times when it was essential for her. Further examples confirmed this sentiment. One individual discusses his uneasy feelings at accepting a disabled parking space and the perceptions that this held for him:

I could get a disabled space outside but I dinnae want to just because it's like, I dinnae want attention drawn to the fact that (...) I could do with a space sometimes, see after 5 O'clock! (Sam 1370-1373)

This individual talked very openly about the loss of his limb and was very keen to demonstrate his ability to maintain an active and high-functioning life. While he used the term "disabled" in reference to himself he did so reluctantly. In addition, this term seemed to have been adapted to suit what he felt was appropriate to him. The discussion of disability as a concept or categorisation led to his discussion of other contact he had with what he described as people who were "handicapped". In his discussion this term was used to describe those with a mental as well as physical disability:

You know how some people are uncomfy like if a handicapped person had fell or something like that. Some people are like 'Oh, oh'. I think I'd be great at that. I just think that's... No that I look at myself. I just feel like what you said there you look beyond like somebody's missing a leg or an arm or they look really [pause] You know how some people handicapped can almost look kind of scary, you know what I mean. (Sam 926-921)

This conceptualisation of disability presents "disability" and "handicapped" as qualitatively different. This allows him to accept the identity of "disabled" for himself with its implications of physical disability and reject the identity of "handicapped" with its

connotations of mental disability. Similarly, the perceived categorisation by others posed a concern for some. The perception that others were treating them differently because of their amputation caused a feeling of unease, particularly when they felt they were being labelled or categorised in a way that did not fit with their own self-identity. The use of particular language such as the term “handicapped” held connotations that they were unwilling to accept in relation to themselves:

And you get called handicapped which is really annoying ‘Oh there’s a handicapped elevator’ [laughs] (...) They don’t mean anything by it though, they just think that someone is handicapped - that’s what they use. I had the really odd sensation of when I was in a wheelchair everybody used to hold open doors and virtually salute me because I had lost it in Afghanistan [laughs] and I felt so embarrassed about that as well because there were times when I was like that. (Gareth 563-572)

This experience highlights the difficulties of negotiating one’s own personal identity in the face of the perceptions of others. By feeling embarrassed by the wrongly assumed reason for his amputation and the misclassification of him as a returning soldier, there is disquiet at feeling a pressure to explain his personal situation or allow this wrongly made assumption of his reality by a stranger.

Whilst renegotiating personal identity can be problematic, there was also a sense that accepting and categorising one’s self could be beneficial and in some way actually provide a buffer of sorts, a new found sense of confidence and courage:

I used to get embarrassed but now I just don’t – I refuse to be embarrassed – it used to be a big thing so I think now also I have the courage to speak up and defend myself when I feel that I am being treated wrongly because of my disability. (Penny 388-390)

While function and ability were paramount for most individuals, coming to terms with a change in physical appearance was also of importance. This adjustment of body image includes reconciling their previous, non-amputated appearance with their new missing limb appearance as well as their appearance while wearing their prosthesis. Recognising that their personal identity now had to include the amputation and the prosthesis was a major adjustment for all. For some individuals, the loss of a part of their body made them feel like less of a person and they found it difficult to reconcile this:

You would expect it in your own mind that you without the leg, you are not a whole human being, that's the way I look at it. (Gareth 382-384)

Upward comparison to a pre-amputated physical self, both in terms of appearance and ability, often resulted in a difficulty of renegotiating current state and accepting limitations:

I was a complete sun worshiper and I would walk for miles for the perfect beach and take my lunch and books and being in Northumberland, I was in heaven, miles and miles of beautiful beaches and I used to walk, park the car, walk across fields and tracks to get there and it was just great but that's all gone, I'm not that person anymore. (Gareth 90-93)

Suggesting that he was “not that person anymore” indicates a difficulty in reconciling his changes in ability and appearance from past to present. Rather than a determination to maintain his previous identity and sense of personal self through positive adjustments, he focuses on the limitations imposed by his new reality. An idealised version of his previous identity means that the current comparison is necessarily unfavourable. Again, his personal identity is based very much on function and ability, without which he no longer feels like himself.

In some cases however, the prosthesis was seen not as limiting but as a means to facilitate an improvement. This individual used the prosthesis as a chance for positive

reinvention of herself and a removal of one negatively perceived physical aspect which had always been part of her self-definition:

I had one normal leg and one wee wizened leg when I was younger and hey, if I'm going to be an amputee, I'm having two legs to match. The technician used to dread me coming in for the final fitting to match them up and I thought, well why not. (Gayle 370-372)

Here the prosthetic device is giving her the opportunity to dramatically alter her appearance and identity from one which she had been unhappily living with since childhood. In a sense she is able to use the amputation as a chance for reinvention of her personal identity and no longer be the girl with the “wee wizened leg”.

Individual attitude and adjustment

Individuals gave a strong view that in all cases adjustment to amputation would be affected by personal attitude. Successful rehabilitation and adjustment to amputation was thought to be strongly influenced by the individual. However, this was not thought of as an additional component but as a forced choice due to their circumstances. Their desire to either actively try to improve life and to adapt as best they can or to accept defeat and give in to a less fulfilling life were stated as the only two options available to them. This perception was expressed by the majority of participants who considered them self to be actively influential in their own rehabilitation:

But, in that situation, it's quite simple, you've got two options, you can either say 'och that's the end of life', curl up and have no life or you say, 'right it's a challenge' I mean some of my golf friends say 'I could never do what you do, play golf with one leg, I would give it up'. That's pretty defeatist. (Andy 189-193)

Individuals reported that a personal identity including a positive outlook and an active role in rehabilitation put the end result in some way under their control. That they could

decide to react in a certain way gave them a sense of control over and ownership of the situation:

You just get on with it, it's all you can do. It's either that or you just crawl into a hole somewhere and make your life miserable - it's not worth it. I am positive; I do whatever I can, just live independently. (Gayle 66-69)

Other individuals reported that their previously held perceptions of what limb loss would be like suggested that adjustment would be beyond their capabilities. However, the reality of having little choice other than to adjust and cope or risk losing the life you wish to lead was enough to convince them otherwise. This becomes less of a choice and more of a necessity for survival:

If you'd had said to me before the accident, you'll lose [sic] a leg, i'd think i would have said i'd rather be dead. Prior to it happening, it sounded like such an horrendous prospect & would never have thought i would have coped at all. but i think people are just pretty good at coping with whatever is put in front of them, You don't really have a lot of options. I now see having a prosthesis as inconvenience. (Sean, email 152-156)

The dualistic and stark perspective offered as “be positive or give up” gives the perception of having the “option” to choose which way to react but with the caveat that their options are undeniably limited. As such a positive attitude is not really a choice but actually a necessity.

Living with amputation presents a variety of challenges in terms of adjusting physically and psychologically to the loss of a limb and all that this entails. In the course of this adjustment, many individuals reported positive personal growth as a direct result of their amputation. For some this experience gave them a new positive outlook on life. One individual describes how his experience has made him more aware of the need to support

others in need during ill health given his own need at that time. Not only did his experience give him a sense of empathy for others but also gave him new appreciation for his own life. His experience allowed him to recognise the importance of giving time and support to others in need and for this he was grateful:

I found it quite satisfying from a purely personal point of view but it changes one's attitude to life. (Andy 269-277)

This sense of empathetic development was expressed by several individuals, some of whom were actively putting their new found skills into practice by becoming volunteer peer support visitors for new in-patients. Similarly changes in ability to empathise with others are highlighted by one individual and this appeared to have given him a new role within his group of friends as someone they can talk to about their problems. Not only does he see the benefit to them but he also feels good about himself in his ability to have coped with a traumatic and difficult experience. This has had an effect on him, not only with specific regard to the amputation, but he can apply it to other areas of his life and that of others:

I feel pretty like nothing would phase me now after being through that and I just feel like it's quite good sometimes as well when my mates or people have like worries or complaints I'm kind of always being like an agony uncle almost like with my mates and that (...)it's not a good thing and I don't go on about it, ever, but if somebody's moaning at me or getting upset then it's easy for me to say 'look at what else could be' (...) It always seems to me, and it's quite a good thing for them as well I think, a sort of leveler, making them see that you know 'I'm no that bad'. (Sam 147-159)

While amputation may present certain imitations, these can be overcome and in some cases replaced with more suitable activities. While not able to do everything one wants to, the ability to make the best of a situation and maximise what you can do was a positive outcome for many; for example, playing golf as often as possible for exercise or replacing

football with swimming. A positive outcome for one was being forced into early retirement due to his ill health but taking on the new role of house husband and active father. He describes the new relationship with his young son that his new situation afforded him:

I did have more time to do things with him. He's always been very technical so I could take him out to shops where we could buy things. I couldn't do biking but I could help him with the mechanics of the biking and stuff like that. One comment he made, I think it was just a few months after the amputation - he said, "Dad, in a way I'm quite pleased that this has happened because you have been able to spend more time with me". (Neil 170-174)

While the amputation may have prevented him from continuing with his job or many of his previous hobbies, he felt that his positive attitude and determination to succeed allowed him to find new ways of defining himself. Thus he created a new sense of personal identity, not completely different from his previous self but merely an adapted version. This message of adaptation in maintenance of personal identity forms a central part of the experience of these individuals.

Defining normality

The concept of normality has to be renegotiated post-amputation. "Normal" is redefined to incorporate new perceptions of physical appearance, function and personal identity. This re-characterisation of normality must combine all of these new aspects of life while also acknowledging previous realities. For each individual this seems to take on a very individual and personal meaning, with there no longer being one acceptable definition of "normal":

I mean, again, there is no such thing as normal. What is normal for me will not be normal for someone else. (Tom 267-268)

Defining, achieving and maintaining a sense of personal normality was vital for the majority of individuals post-amputation. Being happy with one's life with whatever priorities the individual has identified becomes the goal. This goal may adapt over time as priorities change, moving away from aiming for "normal" in terms of basic abilities to "normal" as defined by previous own abilities and personal priorities:

for someone like me who has been in pain and has been disabled by their illness, you just want to get back to normal, in other words, I just wanted to walk. But then as you recover both physically and mentally and I think mentally and psychologically, that's a large part of it, you want to be more like the person that you were and I think your own expectations change. That's what I've found anyway. (Penny 78-82)

What may be thought of as basic or fundamental functional aspects, such as walking and returning to independent living, are initially goals but as these are achieved they are replaced by more personal goals such as returning to work, continuing with a hobby or maintaining family and social roles. As such, the notion of "normality" is not only based on personal relevance but is also a dynamic concept which changes over time.

Normality is characterised by different things for each individual but with the common factor of having the aspects of one's life that are personally relevant at the centre. A determination to continue life as "normal", to continue to be seen to be as capable as prior to the amputation was highlighted:

I worked maybe 8 days in a row, all day every day and never stopping, I won't stop till it gets dark [laughs] I've always been like that (...) and I probably do too much now cause I want to prove to myself that I can do this. (Sam 115-118)

This shows a great determination to continue functioning as he had before the amputation which for him was mostly referring to being self-sufficient and continuing to

provide for his partner in the home, even if he wasn't able to provide for her financially by going to work. He had a need to fulfil the role of "man about the house" as he had before. This dominated his sense of personal identity far more than any physical appearance aspects which, although present to a smaller degree, were far more related to social aspects of self.

For other individuals returning to normality meant restoring the relationships and home life they had been enjoying before their amputation. This description of the accident which led to amputation refers to the disruption this caused this individual and the frustration she felt that her way of life may be in jeopardy:

We were really happy and I hadn't felt that for such a long time and then it was like Bang! Somebody had just pulled the rug out from under my feet and I thought oh! And I thought Look, just SORT it. I just wanted to get back to how it had been with ((partner's name)). (Holly 544-546)

In addition to functional and social aspects of personal normality, the desire to return as much as possible to an appearance which would be comparable to that of a pre-amputation reality features in individuals' experiences. For several participants, the ability to wear particular clothes and shoes was central to their own self-identity. Looking and feeling good about one's self was highlighted as being not a minor matter but of central importance in maintaining self-identity and sense of normality. This was not necessarily related to a perception of others but more a sense of internal well-being and satisfaction. In the following extract, while physical and functional changes are paramount, a sense of mourning is expressed for the loss of her fashionable shoes which were very much part of her personal identity and normality:

Standing up after being in a wheelchair for 2 years was fantastic and initially all I wanted was to walk. I wasn't really interested in what it looked like although the thing that actually grieved me the most about the process was having to give away my shoes. I used to

run around in 3 and a half inch heels, never ever did I wear flat shoes and so the only cause of my grief was losing my lovely shoes. (Penny 44-48)

This individual used fashion, in particular her shoes, to help her develop her personal identity, not only the person she presents to the world but also in order to satisfy her own sense of self identity. The reinstatement of one of her identifying features, while initially not as important as the more fundamental function of walking, became important to her as she reassesses and redevelops her self-identity.

Chapter Summary

The main findings of this chapter reveal that, while the prosthetists and individuals share an understanding of some aspects of the impact of amputation on personal identity, there are a variety of areas where this understanding differs. Initially, the way in which an individual integrates the loss of a limb and the use of prosthetic device into their personal identity is viewed as being central to the experience of rehabilitation by both parties. However, the way in which this meaning is understood differs between the prosthetists and the individuals. Similarly, while both groups are of the opinion that the attitude of the individual has the potential to impact on their rehabilitation, this is considered to be a defining factor for the prosthetists and capable of negating clinical input. Individuals who have lost a limb expressed the understanding that having a positive, active role in rehabilitation is not a choice but a necessity. They also appreciated the potential for changes to personal outlook following amputation. Finally, a shared understanding of the goal of returning to a “unique normality” following amputation is revealed with the multifaceted nature of this concept from the individuals’ perspectives being highlighted.

Attempts to negotiate and make sense of personal identity form a large part of the reported experiences of both parties. While the prosthetists report an awareness of the impact of such an experience on the lives of these individuals, their own understanding and

assumptions of this impact is often contrary to that of the individuals themselves. Having no personal experience of limb loss, the prosthetists' views are based on their clinical interpretations of the impact of limb loss and also the application of their personal views. The prosthetists' narratives reveal tendencies to ascribe categorical labels to patients, creating a dualistic divide between disabled and non-disabled or those accepting or rejecting the status inferred by their amputation. These categories are based on what the prosthetist perceives to be the "mind-set" of the individual and subsequent judgements of the patient's ability are based on this. These assumptions are displayed in a static form, once a patient has been categorised the prosthetist regards their enthusiasm and ability to participate in rehabilitation as set. With this categorisation comes a level of assessment that some patients will be less willing to engage in the rehabilitation process and are more likely to take on a "sick" or "disabled" role. Individuals who resist this label are judged as being more likely to attempt to overcome the challenges presented to them and to relish the prospect of accepting and living with their new situation to the best of their ability. Paradoxically, within the prosthetists' narratives individuals who "display" their disability are also identified as being the best examples of well-adjusted patients while those who prefer to hide their impairment are considered, in some cases, to be denying the severity of their circumstances and are therefore not adjusting accordingly. This contradiction between the view of identifying oneself as "disabled" as being negative and obstructive on one hand, while positive and accepting on the other shows a discrepancy between individual prosthetists in their understanding of the patients' experiences and the impact of impairment on identity. In either circumstance, the application of identity categories and the assumptions that prosthetists may make on this basis offer a potential area of concern within the rehabilitation process.

In contrast to the dualistic, static view of identity offered by the prosthetists, personal identity as described by those individuals who have lost a limb is viewed as a dynamic

construct. This is altered in light of a variety of influential factors such as personal circumstances, changes in technology, time or pre-amputation perceptions of themselves. At certain stages of their rehabilitation individuals may hold particular views of themselves, however these are very much context dependent and are able to adapt and develop according to changes in circumstances around them. In contrast to the prosthetists' views, for individuals who self-identified as disabled, in the majority of cases they were determined to integrate the new physical challenges into their previous self-identity and took pride in being able to overcome limitations. These individuals were satisfied with identifying themselves using disability terms as they felt that this was not limiting or self-defining but rather indicated their positive acceptance and adjustment to their new life circumstances. In addition, for those who did not wish to label their identity in this way, this centred not on a lack of acceptance of their circumstances but on a determination not to allow this one aspect of their life to become central to their self-concept. This was particularly as they felt that any differences in ability were negated through the use of technical devices or through achievements elsewhere. A desire to minimise the focus on their impairment in the construction of their self-identity allowed them to focus on other aspects of their self which were equal to others or which they felt were more central in their self-recognition.

In terms of the attitude of the individual and the impact that this will have on the rehabilitation outcome, differing understandings are evident. Active participation of patients in the rehabilitation process and their personal attitude are deemed by the prosthetists to be a key defining factor affecting their ability as clinicians to achieve their goals. Where goals are not met or where the outcome is deemed as being less than satisfactory from the prosthetists' perspectives, there is a suggestion that the patients' attitudes are a major contributory factor. The majority of prosthetists suggest that patients are positive and active in the rehabilitation process. However, where patients present with what the prosthetists consider as being a negative or obstructive attitude, this is viewed as being instrumental in

suboptimal rehabilitation outcomes from the prosthetists' perspectives. Individuals' post-amputation experiences determine that a positive, active attitude offers a sense of ownership over the set of circumstances in which they find themselves. While most share the view that a positive and active role in rehabilitation was important, this is viewed less as a choice and more as a necessity for appropriate survival. Rather than being a feature of personal reaction this is seen as a forced option, to refuse to cooperate or actively participate to the fullest degree is tantamount to giving up on life which is not a viable option. Where the views of patients and prosthetists deviate in this study is with regard to the level of emphasis which should be placed on the level of influence the patient has on the rehabilitation process. The prosthetists perceive the patients' attitudes as being highly influential in the process to the extent that the "wrong" attitude can entirely control the outcome. This focus on the role of the patient minimises the prosthetists' own role or responsibility within the partnership to overcome any obstructive issues in order to achieve the optimal level of rehabilitation. When patients discuss their personal attitude towards rehabilitation it is very much with the understanding that they had little or no choice to react in any other way. In addition, they see their ability to adapt and adjust in a positive manner as a personal achievement, with unexpected, positive changes to their life outlook being cited as a result.

Finally, both prosthetists and individuals in this study cite a return to a level of normality that is relevant to the individual as a key goal for rehabilitation and prosthesis use. Difficulties arise however through conflict between expectation and experience for both parties which can often lead to frustration and dissatisfaction. Each agrees that the priority of rehabilitation should be returning the individual to a level of pre-amputation "normality" and that this should ideally be defined by the patient. Both parties are of the opinion that "normality" is a relative rather than absolute state and that any attempts to define a standardised version of the concept were futile. In the majority of cases normality is deemed as referring to personally relevant functional aspects of recovery from limb loss and the use

of a prosthetic device to enable this. However, public appearance also ranked highly in the priorities of individuals with limb loss. Individuals cite their main priorities for their device as enabling them to fulfil their goals and maintain whatever function they consider to be central to their own sense of personal identity. When patients express dissatisfaction with the device or rehabilitation process this is often on the grounds of restrictions on who they perceive themselves to be that were viewed as beyond that which they expected. While the prosthetists in this study report their understanding of the need for personal goals and priorities, their expectation versus experience is different to that of patients. Prosthetists perceive that patients often have what they consider to be unachievable expectations of their device in terms of how it will integrate into their lives. During the clinical process, patients report a lack of understanding and empathy from the prosthetists with regards to their specific needs and priorities. This suggests the need for greater explicit examination and inclusion of these priorities in the rehabilitation process as well as a fuller involvement of patients.

Chapter 5: Social Identity

Introduction

The effect of amputation, and subsequent prosthesis use, on the sense of identity within one's social context emerged as the second theme in this study. Personal identity was defined in chapter 4 in the context of James' (W. James, 1890) "I" or the way an individual views themselves internally. Social identity reveals the conceptualisation of "me" or the way an individual views themselves in a social context and how they consider themselves to be viewed by others. As with personal identity, social identity is likely to be subject to change given the individual's new circumstances.

The way an individual feels they "fit" in a social context is revealed as a theme of key importance within the experience of limb loss and prosthesis use. For some, the need to maintain a socially acceptable self in both appearance and ability is of great importance and is often the key reason for using a prosthetic device. For others, striving to maintain a social identity that is not defined by their limb loss becomes a priority. Indeed, maintaining or creating a social identity in spite of the amputation becomes a goal for many individuals. Often the reaction to amputation that an individual perceives within a social setting comes not from a particular event but from that individual's expectation of the response they will receive. The way in which this reaction is perceived may impact not only on the individual's acceptance of the prosthetic device but on their adjustment to amputation overall. The range of understanding of these concepts between prosthetists and patients offers potential for disparity in priorities and impact on rehabilitation. Perceptions of amputation and disability within society impact, on not only the individual's view of themselves, but also in the prosthetists' view of their priorities and reactions to amputation.

Social support within this study is discussed in terms of contribution to rehabilitation and adjustment. While both individuals and prosthetists identify the need for such support, be it

from family, friends or other social groups, there are differences in understanding relating to the role that it plays. For the prosthetists, concerns are raised regarding the balance between support and dependency. They also raise concerns of the impact of social influence on expectations of rehabilitation and the additional pressure that this may place on the individual. In addition, the impact that this has on expectations of them as clinicians is critical. The experience of the individuals shows the intrinsic role that they feel social support plays in their rehabilitation but also highlights the difficulties for those who do not have such a network in place. Furthermore, concerns for protecting family members from undue changes or the implications of such may become problematic.

Finally, social comparison plays a large part in the experience of limb loss. This comparison is made on a variety of internal levels with pre-amputation or ideal versions of oneself. Similarly comparisons with able bodied and others who have experienced amputations are found to colour expectations as well as being used as coping strategies. Prosthetists and individuals accepted the benefit of such a comparison; however concerns were presented by prosthetists of the potential for difficulties in terms of raising unrealistic expectations of rehabilitation. Again, while this concern is for the well-being of the individual, it also presents a difficulty for them as clinicians in terms of contending with these expectations in a clinical context. The individuals in this study felt that, in the main, comparison to others with a shared experience was a valuable resource in their rehabilitation. Comparisons to others were thought to play a large part in the coping mechanisms of individuals, giving encouragement for potential achievements in rehabilitation.

Prosthetists' Experience

Social interaction

The prosthetists' narratives reveal a notable belief that social integration plays a large part in the adjustment of an individual to amputation. Firstly, during the limb fitting process,

prosthetists considered the perceptions of others as being a priority for the individual. This appeared to be mostly in relation to hiding the amputation from others and continuing to present a non-amputated self to society:

It's how other people perceive them that's important. I don't think they would ever get to the stage that they look down and think that that prosthesis is part of them but they want other people to think that. (Chris 229-231)

In the prosthetist's opinion it is the presentation of a "whole" self that is important. The individual's view of him or herself notwithstanding, it is the portrayal of a "whole" self to others that is considered to be significant. This may or may not reflect the views of the individual and it is important to consider the implication that this opinion may have on clinical decisions in terms of limb prescription. The implication that the perception of others is an important aspect of prosthetic limb use may reflect the prosthetist's rather than the patient's view. The application of personal views in the interpretation of the patients' needs was openly discussed by one prosthetist, with particular reference to social interaction:

You put your own feelings on things and I'm quite conscious that I wouldn't want people, if I was functioning in a way that a lot of people do, I wouldn't want people out in a waiting room which isn't solely amputees. (James 213-215)

Here, the prosthetist highlights the belief that if he were to lose a limb, he would be uncomfortable displaying this to able bodied people. This was due to his assumption that this would be socially awkward and lead to negative reactions from others. From this follows the perception that other individuals would have the same reaction. This may lead again to clinical decisions being based on the prosthetists' personal perceptions rather than an explicit expression of such priorities from the individuals.

The perception that presentation of a “whole” non-amputated self in public should be a priority was related to the notion that the only version of oneself that will be socially acceptable is that of a non-amputated, able bodied version:

Many people clearly feel accepted socially only when they have their leg on so most want to wear one. Sometimes they are troubled by a knee lock being unreliable, for example, and this can be embarrassing for them. (Ann, email 95-97)

The suggestion that a technical fault that may expose their limb loss would be embarrassing gives rise to the implication that limb loss on a whole is equally unacceptable. Again this may be reflective of the prosthetist’s own perceptions of the patient’s interactions with others based on their own assumed reactions. If these are supported by explicit instructions and discussions with patients regarding their priority then this would be a clinically sound decision. However, concerns must be raised regarding the level of influence of personal opinion on clinical practice.

The prosthetists in this study highlighted their perception of the relevance of the views and opinions of family and friends in the post-amputation experience on several levels. They indicated firstly that patients appear to worry, often needlessly in their opinion, about the effect that the limb amputation or prosthesis use has on the individual’s friends and family and their perception of the individual:

I think most of the time people have more of a worry about it than their family would. I remember one guy saying to me : I don’t want this to spoil my daughter’s wedding photos and I kind of thought : Your daughter will be quite delighted that you’re there , never mind the fact that you had to use your wheelchair because you got tired. (Eve 441-444)

The application of the prosthetist’s own assumptions here dismisses the patient’s own personal concerns. This displays a discrepancy in understanding of the experience of the

individual and again raises concerns of the potential for the application of the prosthetists' own perceptions in the clinical process.

In addition to the social perceptions of others, the social roles which an individual plays were also highlighted as being a priority for the prosthetists. The ability to maintain social roles was thought to influence the ability of the individual to maintain their place in the family, work environment or community as a whole. The prosthetists identified the importance of recognising these roles and enabling them through prosthesis use:

If it was a person who, say, for example became a transfemoral amputee , if he was the one who did all the stuff and he was the only one who drove in the family , he took everyone around to the shops and that, that's something that they would have to deal with as he may not be able to do that again so that's something that it's not just a case of looking at the patient himself and his own environment it's about looking at everything else as well. (John 72-76)

This identifies the need to allow the patient to maintain their pre-amputation roles and the need for holistic consideration of such influence within clinical practice. This highlights the prosthetists' perceptions of what they consider to be a key aspect of their clinical role and a priority for their practice.

Social support

Prosthetists highlight social support as an area of great importance within amputation and prosthesis use. The prosthetists, however, raised concerns over the appropriateness of this support and the impact that it may have upon the rehabilitation of the individuals. In the opinion of the prosthetists, a level of social and in particular familial support is essential for positive rehabilitation post amputation. The prosthetists view social support as pivotal to good rehabilitation and conversely lack of support can hamper it:

I can think of two upper limb amputees who have lost both hands and one is incredibly successful now. He does very well, very fulfilled family life, work life fabulous. Somebody else with perhaps not as good a support of social circumstances, having said that, but is in a dreadful state. You know, not engaging in life, not going out, having problems with their family, not able to work and it's social support networks that are missing and an ability to see the best and to try and look forward because it's not easy for either of them it's certainly not easier for one person to have no hands than it is the other. (Eve 328-334)

The perception here is that social networks are the key to all other aspects of the rehabilitation. While both are comparable in their amputation status, the prosthetist rates one individual as succeeding far more in terms of returning to a life comparable to that of pre amputation than the other. While this interpretation may be correct, it is important to recognise that not only is this “success” being determined by the prosthetist rather than the patient but also that the weight of responsibility being put upon the social networks may be over stated. The prosthetist appears to be defining social support as having the potential to “make or break” rehabilitation and thus effectively discounting the individuals’ experience.

While the prosthetists identify social support as being valuable in terms of rehabilitation, the nature of this support is brought into question. The all-encompassing term of “support” suggests a helpful, positive and welcome aid from friends and family. However, prosthetists suggest that while social support is required, too much or inappropriate support may be maladaptive. The prosthetists are of the opinion that excess support can lead to dependence thus limiting maximum, positive rehabilitation:

Like you get some people that you end up with you being the person that puts the limb on and does everything and you're thinking : You must do this at home and then you realise they say: Oh, no, my son does it. (...)But they're perfectly able to do it themselves but they'll maybe say: Do you know what, I'm seventy and my son needs to do it but they don't need.

They're perfectly able. There's no other health issues, you know, with their upper limbs or anything. You should manage. It's just that you don't want to almost. They feel that they do need taken care of. (Kate 407-414)

In short, the prosthetists perceive that social support has a significant role to play in rehabilitation but that the specific type of support that is offered may help or hinder the process. This places a rather large onus on the social support network as, not only an essential aspect of rehabilitation, but also a pressure on family and friends to provide the “right” type of support as defined by the prosthetist. A further concern raised by the prosthetist is that families can unwittingly hamper rehabilitation by raising expectations inappropriately. Prosthetists recognise that family members want to encourage their loved one to remain positive and have an expectation they will return to their pre-amputation state of physical health and ability. There are a variety of medical and individual factors which will contribute to the level of ability achieved post amputation and this may not be appreciated by family members and the individuals themselves. Prosthetists suspect that by giving what they deem to be positive reassurances, family members may be raising expectations beyond the current capabilities of the individual. This may either pressurise them to achieve beyond their means or disappoint them if they fail to reach the elevated levels their family expects them to:

Well, families, they try to be helpful to the patient by saying: Oh, don't worry, you'll be going up and running, no bother, or going up and walking and doing this and that so you are not only trying to manage the patient's expectations but you are also trying to manage the family's expectations. (John 69-72)

The perception that potentially raised expectations may have a negative impact on the individual both psychologically and physically is concerning for prosthetists as clinicians. Of additional concern is the added complication that this adds to the prosthetists' role in

terms of “managing” the expectations and tailoring them in such a way that they are achievable from the prosthetists’ point of view. This awareness of fostering appropriate support poses a difficulty for clinicians in understanding this impact on the individual and on the rehabilitation process:

They think they’re being helpful by encouraging, so, you’re right. There’s got to be a certain amount of understanding of people, of what can physically be expected and the difference between encouraging and badgering, so, it’s not an easy thing to do because, like I say, some people will become depressed and not have the motivation to do something that’s physically difficult. They need that but, at the same time if they’re pushed too far then that’s not good. (Eve 470-474)

It appears that social networks are deemed to be essential for rehabilitation but there is the additional pressure of being able to provide enabling support as opposed to pressure on the individual. In this case the prosthetist recognises the difficulty that this presents for the family and friends of the individual. While this is mainly presented as a concern for the individual from the prosthetist, the added dimension of complications for their role in terms of having to contend with the potential influence of social networks on expectations is also prominent in the prosthetists’ experience.

Social comparison

In the period of rehabilitation following amputation, contact with other patients leads to a natural comparison between self and others. Comparison with others who have shared the experience of amputation offers a unique insight to the individual. While recognising the benefits of such social comparison prosthetists also raised concerns of the potential impact this may have on the individuals’ expectations of their own rehabilitation experience.

Interactions with others who have experienced limb loss were identified as a key element in the rehabilitation process by prosthetists. This referred to both informal and support group

based contact within the patient community. The desire of individuals to discuss their amputation with someone in a similar situation appeared to the prosthetists to be an important outlet for concerns and source of reassurance:

I think that they definitely do and very occasionally somebody will say something that you just think: I didn't realise you felt like that or whatever and sometimes they don't say it to you, they say it to somebody else. They say it to another person in the room or they start talking to another amputee. (Chris 444-447)

Prosthetists acknowledge that it may be easier to discuss amputation with another person who has gone through the same experience. They acknowledge that while they have extensive clinical knowledge of amputation and subsequent prosthesis use, they have no personal experience of it. The shared experience offered by another individual allows a discussion of amputation specific feelings and knowledge that the prosthetist cannot provide. This also offers an insight into the role of the prosthetist and the relationship that they have with the patient. The lack of a shared understanding may interrupt the clinical relationship as seen by the prosthetist. While the importance of this shared understanding is acknowledged by the prosthetists, it also appears to create a slightly uneasy reaction in some cases:

It must be the only appointment where someone would ever go to when you are sitting half-naked with someone else saying "What's that you've got there?" And they do talk to each other. It's actually... I'm still not sure about that after all this time. I sometimes think: 'Crikey, would I like to be in here' I'm not sure. But then in that situation you might feel differently? (James 153-156)

The need to discuss one's experience is recognised but perhaps not fully understood. While this may not be directly problematic for the individual, this extract does highlight a

lack of full appreciation or understanding of the experience of the individual and the importance to recognise the individual's needs over the personal reaction of the clinician.

The provision of structured rehabilitative peer support while being recognised as important was, in the main, thought of as being the responsibility of specialist charitable groups. The perception of the prosthetist in this extract reveals the differences in the relationships between the individual and those providing either clinical or moral support:

Letting them meet other amputees, someone that's maybe of a similar background to themselves you know and aetiology, you know a similar type of person. That's where the Murray Foundation comes in and they talk about the difficulties that they have because I think that's part of it. They're not likely to discuss maybe some personal issues with me. They maybe discuss them with someone who's, it's the wrong way I'm going to say it, but they sort of elevate you in the clinical situation, sort of talking. Although I don't want that to be the case we all sort of do it maybe when we go to the doctor. (James 477-483)

This prosthetist perceives a barrier here in terms of the role which the individual expects him to play and the balance of power within this relationship. This experience that the individual may hold the prosthetist in a different light than a fellow patient, with whom he can relate on a more personal level, reveals the prosthetist's perception of his role. The suggestion that prosthetists are held in a regard which makes personal discussions and empathetic support difficult, raises issues as to what he thinks of as being his role within the relationship, particularly with concerns to personal rather than technical matters. In this instance the prosthetist is again underlining that amputation is a personal experience which can only fully be understood by those who have experienced it.

In the initial stages of amputation, the majority of patients spend an extended length of time as inpatients on a dedicated limb loss rehabilitation ward. This is seen to be of great benefit for most patients as they receive specialised care in the company of other individuals

who have recently lost a limb. Prosthetists remarked on the lack of provision for continued support in an outpatient setting:

Some people do feel isolated because when they're here they see other amputees, they get a bit of peer support from each other and then they go back into the community and there aren't many amputees around them. I think the self-help groups are really, really important because they can go back into their own area, not see another amputee, feel that nobody else understands them and they feel quite isolated I think. (Eve 30-34)

The need for individuals to normalise their circumstances through interaction with others who have shared the experience is perceived by the prosthetists as being important particularly in the early stages of rehabilitation. Despite this recognition, concerns are once again raised regarding the influence of such support on patient expectations of the device and the service:

Though I think that on the whole I think if they go along to groups that are positive and have a very supportive environment but I think that occasionally, they can be almost detrimental because again they can raise these unrealistic expectations. I mean "Well, Jimmy's got that" (Nicola 216-218)

Such concerns from the prosthetists that individuals may have raised expectations of the clinical possibilities available to them reflect their own concerns as to potential difficulties they as clinicians may have to contend with. The conflict between recognition of the need for support for individuals and the potential negative impact on their own position reflects a need to consider how to address any issues of raised expectations within a clinically appropriate and patient-centred way.

Individuals' Experience

Social interaction

The individuals in this study emphasised that a significant concern for them is the perceptions and reactions of others. In particular they expressed worries about how others would judge them if they noticed their amputation or if their prosthesis use would be noted and commented on. While some individuals shared experiences of negative interactions with others, in many cases the assumption that such a judgement was being made by others was enough to cause them concern:

that's just something that I don't like, people seeing me without my leg. It's really, I don't know if this is weird or not but it's kids that I worry about, and I know they're not gonna say anything, meaning it to be nasty or anything like that but I know what I'd have been like as a kid. (Sam 83-85)

His main fear is that of his amputation and prosthetic limb being brought into the public arena and the reaction that he assumes this would provoke. In this instance, his desire to avoid drawing attention to himself and his amputation is based on his perception of what the reaction would be rather than on any actual instance of a negative reaction. The reason for this discomfort appears to stem from the thought of being considered different in terms of ability or appearance and the negative connotations that are perceived to be attached to this:

You don't want to stand out from the crowd – nobody does I don't think. (Penny 318)

The desire to fit in or to not to be regarded as “different” seemed to be apparent for both the way an individual appeared to others as well as ability. Being able to use the prosthesis to “hide” the amputation was important. In fact, the purpose of wearing a device was exactly that for many individuals and successful prosthesis use was defined as being when strangers were not aware of the amputation:

((On meeting new people)) *You know they meet you and they find out and they say “oh you would never know” And I say that’s the general idea. I say “I’m not going to advertise it!” You know? (Craig 310-311)*

In this case, the prosthesis fulfils the purpose of allowing him to continue to present a non-amputated appearance. The importance of this was echoed by several other participants. The sense of achievement at being able to hide his amputation gives an insight into the level of importance this holds. The success of the prosthesis seems to be determined on its ability to allow the individual to continue to integrate as a fully functional individual in society with little or no differentiation from able-bodied persons:

Appearance is important too, not so much how the actual prosthesis looks, as it’s generally covered up, but more that it shouldn’t be obvious you are walking with the aid of one. (Sean, email 254-255)

As is emphasised here, the cosmetic appearance of the prosthetic limb on its own is less important than the ability that it affords the user to hide their amputation. Being able to “appear” the same as prior to amputation, particularly in terms of gait, is the most important aspect. For one prosthesis user this equated to not only feeling comparable to others but also influenced her feelings about herself, giving her a self-assurance that she would not be looked at or viewed differently to others. The presentation of a limp, a more “acceptable” deficit, appears to have less of an impact on her social identity and allows for a fuller social integration:

Coping, confidence in your ability, confidence that actually I don’t look like a freak, you know, I’m just limping. Well a lot of people walk with a limp that haven’t got a prosthesis. (Penny 449-450)

Using the term “freak” emphasises the perception that she feels other people would have of those who are disabled or different from the norm. The limp is acceptable as this may be a temporary state and not necessarily indicative of an amputation which would appear to be a far more difficult thing to admit to in public for fear of judgement. The need to present a socially acceptable, able self is very strong in this case and reflects heavily not only on her own views of disability but also on her assumptions of society’s views and treatment of people who have a specific disability. This implies that a social identity associated with “disabled” or “amputee” is something which she is keen to avoid. Similarly in this extract the individual discusses the absence of a limp and the ability to hide his amputation as “lucky”:

when people mention to me that you’re limping, I always tell them and I’m actually quite proud of the fact that some people I’ve known up here for years, they may say, you’re limping and I tell them I’ve got an artificial leg and they say they didn’t know that and it’s quite gratifying really. I’m quite lucky that I don’t really limp. (Patrick 310-314)

Through his consideration of himself as being “lucky” at being able to conceal his disability it is evident that the alternative public display of his amputation and prosthetic device would be unacceptable to him. The sense of gratification experienced at being able to successfully integrate socially with little awareness of his amputation gives further evidence of the perceived importance of this in terms of social interaction and acceptance following amputation.

In addition to the desire to hide the amputation, there also followed a contrary opinion from other participants which suggested that as long as the ability achieved was acceptable to the individual then displaying of the prosthesis should be irrelevant. In these cases any concerns regarding attraction that may be drawn due to physical differences were negated

when functional levels of comparison to others were high. This extract describes a change in mental attitude when the individual realised his ability to run on his prosthesis:

The confidence in my stature from being ashamed of being an amputee and wanting a cosmesis on my leg so it didn't look like it was hanging on my trousers and never daring to wear shorts, from that kind of mental attitude and being rather shame-faced about being an amputee because of the stigma carried to you, you know, you weren't able and from that to when I really started running, the mental change in me, you know, I walked confidently, not ashamed to wear shorts because you are an equal of other men. (Tim 117-123)

The difficulties described stem from a perception that, without his leg, he was judged by society as being less able. His perceptions impacted on his willingness to reveal his amputation in public and how he felt about himself. He reached a level of transformation in his attitude through realising his functional capabilities using a prosthetic device. This gave him the confidence to not be concerned about his appearance. This relates entirely to his comparability to others on a functional and physical level rather than that of appearance and the negative judgements that may be made of him. Of greatest importance to him was that he was not in any way less valuable than other men and was physically equivalent.

The perceptions and reactions of others in a social context are clearly apparent in the thoughts of another individual in discussing whether she would be willing to show her prosthesis in public through wearing a skirt. Her reasons for not feeling comfortable wearing clothes which display her device centre almost entirely on what she fears would be the reaction of strangers. Her assumption that she would be viewed critically and might become the topic of discussion is concerning for her:

There's an odd thing about me that almost makes me think I'd be scared people would say: "Look at her. Look at her. Desperate to show everybody that she's an amputee" Do

you know what I mean? (...) That sort of thing. Whispering, "Oh look at her wearing a dress". (Holly 456-459)

Here the belief that society would prefer she hid her amputation and would judge her negatively for displaying it again reflects her view of society's reaction to disability and differences in physical appearance. At a more individual level, not only does she assume that she would be judged, perhaps pitied, but also she feels uncomfortable at the thought that people would be talking about her. Her perceptions that other people would look at and judge her are enough to stop her from doing what she wants to do in terms of wearing a dress. Avoidance of such a situation reveals a sense of self preservation, wishing to avoid being openly judged and discussed. In another statement she felt protective of herself and preferred to keep her situation private. Having a prosthesis that allowed her to hide her amputation offered her a protection from sharing more of her private life than she was comfortable with. Displaying her prosthesis was akin to revealing private information which she felt unnerving:

They know something awful personal and intimate about me and I don't even know them and they could be walking about with high blood pressure and goodness knows all what but I don't know but I don't know because it's not a physical kind of thing so there is that (...) Yes, It's just something that they shouldn't really know, I think. Do you know what I mean or I just think it's such a personal thing because people's jaws drop I'm sure. Other people say this as well. You're out on crutches and it's like a [open mouth jaw drop face] and I feel 'please don't do that'. (Holly 412-419)

Again the reaction of others to her amputation is the real cause of concern for her. Revealing her amputation creates a vulnerability with which she is uncomfortable. This concern is shared by another individual who discusses his unease at agreeing to a disabled parking space at his house. Although this would be useful for him, the thought that other

people would then know of his disability and may put him at a disadvantage is enough of a deterrent to outweigh the benefits:

I think there's a wee bit of a security worry as well. I wouldn't want people, for it to be widespread knowledge that I've lost my leg. This isnae like a terrible area but you know where I'm coming from. Even like kids who chap at the door or chuck stones at the window because he won't be able to chase us. I could get a disabled space outside but I dinnae want to just because it's like. I dinnae want attention drawn to the fact. (Sam 1366-1371)

While he presents this anxiety as a security risk, expressing a fear of reactions even from children, highlights the vulnerability he would feel if his amputation was commonly known about. The underlying issue in this perception is indicative of the way in which he feels his disability viewed by society and his unease at presenting himself as less able than he would have been prior to the amputation.

In addition to the view of strangers or of society at large, as with the prosthetists, the view of close family and friends was also a concern. The recognition that the family have adjustments to make as well as the individual themselves was apparent in several interviews. In cases where the amputation comes as a result of a chronic and long-term illness the combination of relief and adjustment is felt. Family members have to adjust to the new appearance and abilities of their loved one which may cause further difficulties for the individual:

2 years before the amputation, I basically had 2 years of extreme continuous pain which wasn't good for anybody in the family but the pain stopped 2 days after the amputation so that was just a huge relief all round. I think she found it at first pretty difficult to look at me when I did have the prosthesis on, well and before because I was not a full person any more. (Neil 438-442)

In this case, the individual's perception that his wife viewed him as "not a full person" reflects on his own views of himself. This perception would place further strain on him to return to a "full" state. In addition to his wife, this individual was also aware of the impact that his amputation may have on his young son:

Our son had to make big adjustments - he was 7 when I was diagnosed and 9 when I had the amputation but I explained things to him at a level which he would understand. I said to him and a group of other kids, my leg is very painful so I am going to swap it for a new leg and they just accepted that. That was just spontaneous at the time but I realised afterwards that meant a lot to me as well. (Neil 152-158)

Again, while this experience shows something of the reaction of the family to the amputation it also gives an insight into his feelings. This spontaneous explanation offers him a more simplified alternative narrative of his situation. The reaction of family members also caused problems for some who felt overwhelmed by their reaction and in some cases even felt that overshadowed their own need for consolation, as was the case in this example:

I realised I had to tell him that night from the hospital and I realise I had to be really strong and say this and try to say that I'm not in bits and coping with it and I remember going along to the day room and telling him that and he was worse than me, he was so upset, he took about 5 days off work and was in tears all the time and I couldn't be in tears because he was in tears. I think I was slightly inwardly angry that - it's not you - you know. (Gareth 38-43)

The recognition that the amputation was going to impact on his loved ones as well as himself was apparent to this individual even prior to the amputation. However, the reality of his partner's reaction still made him feel marginalised and resentful that he was unable to react the way he would like to so as to accommodate the feelings and reaction of others.

Expectations on the part of the family to achieve particular goals particularly in terms of walking and physical ability served to encourage individuals in their rehabilitation and for the most part seemed to be both welcomed and encouraged by the individuals. However, in some cases, protecting the family from the realities of the amputation became an additional concern for the individual and added to their post-amputation anxiety:

You are thinking how am I going to manage as an amputee rather than how am I going to manage as someone wearing a prosthetic? I tried not to show that to the family when they came in but I had a lot of time to reflect, why has this happened and all that sort of stuff. (Stuart 663-666)

The management of family and friends in these cases was seen to impose an additional burden on the individual as they attempt to negotiate their reactions as well as their own. This was not necessarily an expected outcome but nevertheless adds to the experience within which the individual finds themselves.

Social support

In discussions of living with amputation, the subject of social support came to the fore. From the very early stages in preparing for amputation and the immediate recovery, social support was identified as being of vital importance. For some, having a wide circle of friends and family to rely on was crucial in the initial stages:

The day I came back from finding out I was getting my leg amputated I spent the whole journey home phoning people and even my mum thought that was brave but I just felt I wanted to tell people. I phoned my brother. I phoned my mates because they all knew what was happening and they were all like: You're joking! (Sam 823-826)

In this case, sharing the burden of the diagnosis with his closest family and friends was essential. His need to disseminate the information to people whom he trusts offers him a

way of coming to terms with the situation and gives him reassurance that he had a support network to rely upon. The benefits of sharing the experience with others provided him with an emotional buffer at what was a difficult and stressful time. Emotional support from a social network, beyond even that of family and close friends, can be found in many areas, from work, leisure pursuits or community groups. In this case, being a member of a local church proved to be a source of comfort:

My parents lived in Wembley and I was in RAF hospital in the Midlands and lots of people in the church came up to see me and sent me letters and advice and supported my mum and dad. I'd like to mention that because it did make a wonderful difference - I didn't receive any counseling at all but I got counseling in effect from the church. (Patrick 261-264)

Notably in this experience, the support given by the church was of such benefit that he considered it to be in lieu of professional counselling. The positivity with which he recounts the spontaneous counselling he received from his support network affirms the important role an established support network can play in rehabilitation and adjustment post-amputation.

As well as the positive contribution of social support, the potential difficulties that may arise in the absence of such a network were identified. This importance is underlined by the concern expressed at the thought of coping and motivating oneself if this system of support were not in place:

I think everybody around me as well , my dad, my brother, my mother, they would never let me sort of ...Because I think it would be easy if I never had a good family or an amazing family, an amazing girlfriend and great friends and that. I think it would be easy if something like this happened to you to just sit in a corner and forget about life all the 'gether. (Sam 652-657)

The reliance on family and friends is evident as is the real concern he has that without them he would be unable to cope. This concern was shared by several individuals who expressed concerns that without their support network they may not have achieved the level of rehabilitation that they felt was possible. The support and encouragement given by family was not only relied upon by individuals but recognised as an essential element to their rehabilitation.

This lack of support network was alluded to in several interviews where the individual emphasised the need for independence and personal, emotional strength:

I don't have any support, I can't afford to have limitations so there is nobody going to do anything for me, I know that, even in emergencies, for example, how would I get out of here in a fire, I know I could walk down the stairwell, I don't want to do it but I could do it very slowly, one step at a time, holding onto the bannister, using the stick but I could do it.
(Gareth 532-536)

In this extract, the value of support networks is apparent in its absence. There is the suggestion that support allows an individual to admit weaknesses or limitations, a luxury which this individual felt was unavailable to him. The lack of support network means that he has had to become self-reliant and independent even when this is difficult or poses challenges.

Family members were also identified as giving encouragement to think positively and focus on long-term goals rather than on the initial difficult adjustment:

My mum and dad obviously saying: right, come on! You'll be able to do this and do that
(Sam 833)

This encouragement allowed the individual to focus on the potential for rehabilitation rather than on the negative thoughts he was having at the time. The accuracy of the

reassurance in terms of the potential to achieve the goals that his family were suggesting appears to be irrelevant, merely the assurance that he would progress was enough to give him confidence in his ability.

Similarly, encouraging comments from family members in overcoming psychological barriers such as challenging the perceptions of others was appreciated:

I was speaking to ((partner's name)) the other day about maybe wearing a dress just with my pole and he said "Why not? It's part of you now. This is what you wear every day to go about doing your daily things. You know if people think it looks strange and that you shouldn't be wearing a dress. It's just ridiculous, and maybe you just need to counter those sorts of people." (Holly 405-409)

Social circles of family and friends do appear to provide the individual with an essential level of support both in physical and psychological encouragement. This support can come from wider social networks and appears to be actively sought by individuals. Similarly, when such support is lacking the negative effect of this on the individual is evident which should be considered in terms of its potential impact on rehabilitation.

Social comparison

Prior to amputation and prosthesis prescription, discussion with individuals who have previously experienced amputation is identified as being contributory to helping individuals assess their priorities and make informed decisions regarding their chosen care route. This direct comparison with others in the same situation was deemed vitally important in both practical and psychological preparation for amputation:

I'd talked to other people who had similar amputations. Some used the prosthesis and some did not but that was personal choice and I decided to go with the prosthesis and I was quite happy with that decision (...) that helped both on the physical and the emotional side

which I think are quite closely linked, which was a challenge but I was urged not to let it get me down. (Neil 110-119)

The ability to discuss with others the particular challenges of prosthesis use and to be given the opportunity to question the specific practicalities of amputation is important. That this support and advice comes from individuals who have lived knowledge of this experience adds to the confidence of the newly amputated individual. They perceive this information as coming from those with a shared, direct experience as opposed to the non-amputated professional. In addition, the recognition of the link between the emotional and physical aspects of amputation, and the empathetic insight into this that can be offered in a peer support context, can be a valuable asset in adjustment to amputation. Using direct comparison to others in an inpatient care setting offers this peer support and affords the individual an alternative viewpoint on their own situation. For most, the thought that they were not alone in their situation was a source of great comfort. That other people could understand what they were experiencing and, in addition, that other individuals were perhaps in circumstances worse than their own provided a sense of hope and perspective. The camaraderie experienced while in the rehabilitation ward proved to be vital for many in motivation and encouraging progression and physical achievement. Having someone who was comparable in a variety of ways, for example age, gender, aetiology of amputation, was of great importance to this individual who discusses the positive impact of having a patient whom he could relate to on the same ward:

Me and him went together ((to the gym)) and we could kind of, for me anyway, although it was easier for him because he was below the knee I would look to him and be like “right if he can do it I can do it” and it worked out that we kind of got out at about the same time because although he came in after me, we got our legs at the same time and I think it is a good bit easier if you’ve got the knee joints (...) but that kind of spurred me on, and we’d sit

on the bed playing head tennis and to be honest we actually had quite a laugh in the place and I'd had none of that before he came so... (Sam 492-199)

The transformation of his experience following the arrival of this other patient, from a difficult experience to one in which he felt motivated and encouraged, is vast. He was able to define his own limitations by comparison to this other individual. The arrival of a fellow patient with the same life circumstances and aspirations allowed him to recognise himself and the potential for improvements and adjustment open to him. This companionship also created the friendly, fun environment in which he was far more comfortable. This ease with which they were able to talk, play and relax with each other provided a reassurance that this would be able to continue in his life following discharge. The importance of being able to envisage a “normal” life after discharge and that this will be comparable to life prior to amputation was reiterated in several experiences and was highlighted as one of the key benefits of peer support, particularly while in early hospitalised stages of rehabilitation:

I think it helps because it lets new amputees realise that there is life after hospital. This is not you for the rest of your life, stuck in a wheelchair, sitting at the side of your bed. You can get out and about. OK you may have to have modifications done to your car but you can still drive. This picture of normality and I think that's so important and knowing that there are other people around that you can speak to if you want to. (Gayle 605-609)

The creation of this “picture of normality” and of using others, not only as support, but also as motivation and reassurance, continued beyond that of the immediate post-amputation experience. While initially the key focus is on an overall picture of the potential reality of living with amputation and prosthesis use, comparison to others continues to impact on the individual's view of themselves and on particular aspects of their own prosthesis use. This may include inspiration to aim for physical achievements they see in other individuals or a reassessment of how they see themselves:

I take my hat off to these soldiers coming back from Afghanistan, they all have a tendency to wear a leg only with the metal, there's no padding and they're going around with no sticks, or running or skiing and I think, oh for goodness sake, I'm so blooming out of it. (Andy 349-354)

Looking at not only the physical achievements but also the social portrayal of these injured military personnel caused this individual to reassess his own thoughts on his abilities and provided a wider gauge on which to base his relative perception of himself. Similarly, seeing another individual display their device publically often encouraged others to do the same:

He actually gave me a bit of, because I'd never wore a pair of shorts or like cut offs or anything when I'd been on my whole holiday and then we were just speaking about loads of stuff. We spent about two hours talking and that and then him and his wife went away and the next day I said to Fiona: I'm going to wear short today because if he if he can go about with a pole basically for his arm, there's nothing to stop me. (Sam 1350-1355)

Taking inspiration from this publically confident individual allows for a re-examination of personal social comfort with regards to displaying the device. Seeing others do so serves to normalise the appearance of the device. Again, the ability to compare directly to another person in a shared circumstance allows for a reconsideration and changed perspective of their situation.

While comparison to other individuals who have lost limbs appears to be important in the assessment of post-amputation experience, there seems to be an aspect of direct comparability which is critical. While being able to speak to and see other individuals was, in the main, encouraging and positive, the individual often needed to see a direct similarity to their own situation in order to be able to use it for their own rehabilitative motivation. Their desire for comparison centred on being able to make a direct comparison with a situation in

order to predict the outcome that they hoped for themselves. In situations where the other person being observed was not considered to be directly comparable, the benefit lessened as the contrast between them was deemed too large to be applicable:

Obviously, I showed the guy loads of respect, and I was like Thanks very much. He did help a wee bit: "It's not stopped me doing anything" He lost his leg when he was about eight or something like that. He says: I've met my wife. I'm married with two kids and all this, that and we go on holiday and he was working and that was partly what I wanted to know but I just wanted to see somebody walking. That would have been even better. Any of that, just to see somebody walking from this wall to that wall with an above knee amputation it would have made me feel a million times better. (Sam 1158-1168)

The comparison being made in this circumstance was directly related to the key goal of walking and a return to pre-amputation physical activity. The achievement of all of the life goals that were of secondary interest at this time was not prioritised in his perception of this meeting. That his own focus was so heavily on his physical rehabilitation meant that the additional achievements of this other individual were minimised in his estimation. Here, the comparison with his previous self and the physical capabilities that he was hoping to achieve is most relevant to him, but also presents problems as this comparison requires gradual adaptation and reprioritising of identity and goals.

Potential difficulties were also identified in social comparison, particularly with regards to the qualifications and potential negative impact of volunteers for hospital visit schemes, mostly arranged via charity groups:

They're not counsellors either – they potentially could do quite a lot of harm. If you get someone who goes to see someone and they say, well what's this phantom limb thing – what's that all about and this person..."oh I've had my leg off 20 years and not a day goes past without, oh I've got the most awful pain" Imagine what that would do for someone and

ok you can train them to say the right thing but who knows what they are actually going to say given any particular set of circumstances. They are not professionals, they don't know about client confidentiality. (Penny 490-496)

The voluntary and unregulated nature of the peer support visitors to the hospital is concerning for this individual. While the influence of peer support may be recognised in the main to be positive and beneficial, the potential for negative impact must also be considered.

Chapter Summary

This chapter explores the experiences of post-amputation individuals in relation to their identity and their interactions within their social context. The reaction of others to the post-amputation individual was of great importance. The outward visibility of the amputation to strangers in particular, was a cause of concern to participants within this study. Anxiety arose from the perception that participants had of others' awareness of their amputated limb, and from the perceived unwanted attention that was derived from it. This varied according to the specific social context in which the interaction occurred. In terms of very close family and friends this seemed to cause less of a concern but for acquaintances or strangers the apprehension was often greater. The potential judgement being made of their abilities, circumstances and merely being the centre of attention was of greatest concern. The use of a prosthetic device to minimise this visible difference was discussed by both prosthetists and individuals. While some individuals felt strongly that they wished to hide the amputation from others where possible, others discussed their comfort at having their device on display. Reasons for the hiding of an amputation include feeling integrated in society, wishing to maintain a level of privacy and prevent a sense of vulnerability that occurred when others were aware of their circumstances. In displaying the device, there was a sense that the appearance was irrelevant as long as function was maintained thus making functional ability a priority. The perception of the potential public reaction to amputation and societal views

on disability appears to provide one of the key reasons for wishing either to hide the amputation or, alternatively, motivating to prove oneself as being beyond these assumptions and therefore of being as capable as an able-bodied individual.

The role of social support was considered in terms of its impact on adjustment. Social support and the impact on family and friends were revealed as being key concerns for the individuals. While social support appears to offer positive benefits, similarly the lack of such a network can be seen to have a negative impact. Post-amputation social support has the potential to have a dramatic impact on an individual's rehabilitation and adjustment and an awareness of this by both individuals and prosthetists is apparent. Prosthetists suggest that the nature of this support must be such that the individual is encouraged in their rehabilitation while not leading to dependency. Additionally the effect on the expectations of the individual, in terms of their rehabilitative outcomes, may be impacted upon by this social network. This poses a concern for the prosthetists where such expectations are beyond their capabilities as clinicians and that of the individuals. A sense of pressure to meet the expectations of family and friends was also expressed by the individuals. While on the whole, a strong social network was deemed invaluable to the rehabilitation process and often the encouragement they received through them was central to their recovery, the sense of responsibility to protect them from the difficulties of the process was also felt.

The final intrinsic element of social experience and identity was social comparison. Comparison with others played a large part in the experience of the individuals interviewed. Whether to other individuals who have lost a limb, to themselves prior to the amputation or to able bodied contemporaries, the assessment they make of their similarities and differences on each of these levels has the potential to impact on their own social identity. In terms of comparison to their previous self, the focus is very much on past abilities as opposed to appearance. The prevailing attitude of individuals and of prosthetists in this study showed a focus on presenting a social self which is equal to, if not better than, prior to amputation.

Social comparison to other post-amputation individuals was also evident in terms of assessing rehabilitation progress. The reassurance and encouragement which an individual gains from discussions with other people who share the amputation experience has an important role to play within this group. The experience of losing a limb carries with it very specific challenges which individuals appear to be keen to share with others who have also experienced them. Again, concerns with appropriate support are discussed within the realms of this peer group arrangement. Issues surrounding appropriate discussion and support were raised, particularly by the prosthetists with regard to highlighting discrepancies in experience which may in turn impact on an individual's expectations of the device. These concerns of potentially inappropriate expectations and the impact that it has on the prosthetist's role are further discussed in terms of the expectations of the prosthesis in chapter 6.

Overall the impact of amputation on social experience and identity appears to require a level of adjustment on the part of the individual, not only on how they view themselves, but on how they perceive others to regard them. In addition, the impact of these interactions on adjustment to amputation and prosthesis use has the potential to greatly influence their experience. The influence of social support networks and social comparison in the main were thought of as beneficial to the individuals' rehabilitation but with a caution regarding the potential negative impact these may have in certain circumstances.

Chapter 6: The Prosthesis

Introduction

This chapter details the role of the prosthetic device in life after amputation from the perspectives of both prosthetists and individuals who have lost a limb. A key factor in understanding and interpreting the role of the device are the expectations which are placed upon it. This includes the anticipated practicalities of device use, expected outcome and specific aspects of the device itself. The influences on these expectations and the impact that they may have on rehabilitation are of great importance to prosthetist and patient alike. Such expectations are likely to impact on levels of satisfaction with the device, the service and the success with which the device is integrated into an individual's life. For both prosthetists and individuals, difficulties arise where expectations and experience between these groups differ. Often prosthetists see their role as one of expectation management in order to align the individuals' expectations with the service they feel able to provide. From the perspective of the individuals, these mismatched outcomes are often viewed as a lack of recognition from the prosthetists of their needs.

In the second sub theme, "Living with the prosthesis", aspects of integration and impact on life are discussed. Individuals seek enablement and a return to a pre-amputation level of activity through the use of the prosthesis. This comes with a varying awareness of the limitations and constraints that are placed upon them in prosthesis use. The prosthetists suggest that, while individual enablement is their goal, often the individuals have a lack of understanding of and preparation for the impact of amputation on daily living. Analysis of the experiences of both individuals and prosthetists suggest that the variation in understanding of both groups in these issues may be impacting on the shared experience.

Finally, the priorities of prosthesis use are discussed. For the prosthetists, function is prioritised in clinical practice. However, the particular needs of the individual are not

necessarily always prioritised often being superseded by the clinicians' own perceptions of need or by systematic limitations. The ability of an individual to feel satisfied with their device, and to continue to live a normal life as defined by their circumstances, is very much dictated by these priorities and the ability of the device to meet them. Each individual develops their own set of priorities with regards to the capabilities of their prosthetic device. While these essentially are broken down to aspects of functionality, comfort and cosmetic appearance, it is the meaning that is assigned to each of these and the importance on subsequent adjustment to amputation that is of key importance in this study.

Prosthetists' Experience

Expectations of prosthesis use

In the initial stages of prosthesis use, prosthetists report varying degrees of expectation from patients in terms of what a prosthetic device will offer them and how it will impact upon their daily life. In the first instance, they perceive that individuals view the use of a prosthetic device as an immediate solution to the limitations and challenges imposed on them by amputation. The expectation that the prescription and fit of a prosthetic device will provide a quick, easy, one-time solution is often encountered. Prosthetists report difficulties where there is a discrepancy in terms of the individuals' expectations and the level of rehabilitation that will be needed in order to achieve full, functional use of the device:

What they want to hear is: you're going to be fine. This is going to be...you're going to get a prosthesis, you're going to walk out of here, it's all going to be great and I think it's really important not to say that. That's a sort of short term fix. That will cause a lot of problems later on because that will fester with someone if it doesn't happen and that really builds up some frustrations there. (James 469-473)

Prosthetists feel that part of their role is to encourage the patient to adopt a view of prosthesis use which is more aligned with that which the prosthetists view as appropriate.

Prosthetists see themselves as having a wealth of clinical knowledge which their patients do not have and as such they feel that this should be used to tailor patients' expectations. This encompasses aspects, such as the time taken to prescribe and make the device to the level of physical input needed to achieve a level of functional ability. The prosthetists view the patients as not only having a limited understanding of the complex nature of their own condition but also a lack of appreciation of the rehabilitation that is required in order to reach the level of functioning sought. The prosthetists perceive a common lack of understanding of the practicalities of using a device. For example the physical input needed from the individual in order to fully achieve their potential is often underestimated which gives further concern to the prosthetists. Managing such expectations in order to match the service which the prosthetists are confident of providing becomes central to the prosthetists' understanding of their role.

A variety of sources are identified by prosthetists as influencing patients' expectations and beliefs. Media sources can often portray amputation in ways which are not representative of their experience of a clinical population. This adds a difficult dimension to their role as they attempt to counter these representations:

Ill-informed public opinion, high profile amputees e.g. ones that return from Afghanistan and ones that dance on ice on TV – who are inspirational in their own way – but these people are fair[l]y irregular and generally our patients are old and frail with comorbidities. (Adam, email 137-140)

Prosthetists commonly reported a perception that the focus of the media on exceptional cases, within the world of prosthetics and amputation, raises patients' levels of hope and expectancy in terms of what can and will be achieved through prosthesis use. While such a high level of ability or appearance may be achieved in some cases, the prosthetists are keen to point out the differences between the average amputee and these, more unique, cases. In

particular, they stress differences in aetiology and personal circumstance, which have the potential to contribute to the final level of achievable rehabilitation. The presentation of extraordinary examples of prosthesis use are thought to have a negative impact on individuals' expectations:

I think it can be quite negative because you can have somebody that's quite old, in their 70s and they want to have a limb like soldiers have. They make it look so light on the telly and it's not until they actually go to the store and get a knee or a foot and say that this is the weight that they've got and they just about drop it and think : It doesn't look that heavy and you say : Yes ,but it's all about perception. They've been about their peak fitness when ...the soldiers ((...)) It's completely different. And you'll get somebody wanting to run and I'll ask if they ran before and they'll say they didn't. It's just they see the Paralympics and the soldiers and they want to do a lot more. (Kate 21-29)

It is often unclear as to whether the raised expectations are potentially damaging to the individuals, or to the prosthetists themselves, in terms of the added difficulties it may present to them in their professional role. The perceived lack of understanding of the practicalities of prosthesis use present difficulties for the prosthetists in a professional capacity as they see themselves as having the additional role of managing these expectations.

In other cases where prosthetists point to patient knowledge being influenced by additional sources, this knowledge could be used to enable discussion and in some cases lead to progression in the understanding the prosthetist has of the individual's circumstances. While this easier access to information may raise expectations, this also has positive benefits:

I can see the next generation coming through more savvy on information and maybe putting a bit more pressure and being more knowledgeable. The more knowledgeable the patients are, the more you can get involved in a discussion with them. (Steve 259-261)

In this case, the welcoming of patient knowledge and input into the decision-making process is reflective of other areas of the prosthetists' experience where patient involvement is considered to be essential to successful rehabilitation. However, this is presented alongside the need to apply "pressure" to the prosthetists, putting conditions on the perceptions that the prosthetist has of patient involvement in this case.

Prosthetists also identify other medical professionals as influential in patients' perceptions. Prosthetists perceive a lack of understanding from less technically experienced professionals of the complexities involved in the use of a prosthetic device and in adjustment to limb loss:

We have other medical professionals doing exactly the same thing which is very bad. You know, surgeons and nurses in other places maybe don't have the experience saying: "Don't you worry, you'll go over to the ((rehabilitation ward)) and you'll be up and walking in no time" and I've heard that reported. Patients have told me that whether it's true or not but of course they have all these physical difficulties which mean they don't do as well as they think they'll do. (Eve 271-276)

Misinformed comments are reported to raise the expectations of the individual to levels which the prosthetists feel are unattainable which may, in turn, lead to disappointment if the patient does not achieve these levels. The responsibility once again falls to the prosthetist to manage these expectations and to counteract the misleading information provided. While such flippant comments may be made in an attempt to reassure the individual, there is the suggestion that medical professionals are likely to have their comments taken seriously and therefore should be more cautious in their discussions.

The level of expectation that a patient has, particularly in the early stages of rehabilitation, is identified as being problematic for the prosthetists:

Probably one of the trickiest things we have to deal with I think in our profession that expectation level and something that's raised beyond our control before we even get to have that discussion and sometimes, it's rarely, but sometimes it can be that you're going to have a consultation with your patient and it's going to be confrontational from the start because they want this and you haven't even had that discussion yet and it might not be clinically appropriate or it might not be something that we could even provide even if it was. (Angie 98-103)

Prosthetists are faced with difficulties when the expectations of patients are set, even prior to fitting of the device or consultation with the prosthetist. These expectations may not be within the realms of what the prosthetist considers to be reasonable particularly if the patient believes that the prosthesis will fix their amputation-related problems. The perception that this may lead to confrontation suggests that where the prosthetists are unable to meet the patients' expectations this may be problematic. However, the use of such terminology suggests the attempts of the prosthetists to apply their own perspective rather than a two-sided cooperation in order to come to a mutually agreeable outcome.

Despite the perception that the expectations of the individuals are highly influential in their demands to the prosthetists and their satisfaction with the device, it appears that often these expectations are assumed rather than explicitly discussed with the patient:

I don't know whether it's done very often but I think it would be very interesting for people to ask their patients more often "what are your expectations here?" So you've got a starting point. If that was logged, so to speak, or noted, then it would be interesting to see how often they are met and exceeded in some cases, or not. (Steve 351-354)

The judgements being made on patients' needs, expectations and levels of satisfaction without an explicit understanding of what these are in the beginning of the process suggests a

breakdown in communication. In addition this is further evidence for clinical practice based on prosthetists' assumptions rather than an understanding of patients' needs.

Living with the prosthesis

The prosthetists in this study assert that their goal is to enable the patients' functionality in order to allow them to maintain a normal daily life wherever possible:

When I'm talking about function, I'm talking about returning them to normal activity never mind appearance or anything like that. To actually allow them to do the things they want to do, to walk normally, to go up and down a flight of stairs, to go up and down a slope without having to worry about it, to think about it for anything and that's a long way off some of that but that's what function is to me. (Steve 329-333)

The ultimate goal of device prescription and rehabilitation is to enable automatic and non-intrusive action which emulates a non-amputated, anatomically correct leg. While prosthetists recognise that this may be difficult, often impossible, to achieve, they see their role as providing a device which enables the individual to maintain a standard of living that is personally satisfactory. A successful rehabilitation and the one which gives most professional satisfaction to the prosthetist is one where the individual is living their life the way they want to with no interruption from the amputation:

I would say there's times when people have absolutely no problems and appear to be getting on with their lives with no major issues and by that I often take it well essentially that they are doing the things they want to do and the prosthesis or the amputation is not standing in the way of doing that. (Steve 38-41)

Often the goal of the individual may involve highly physical tasks such as running and climbing or participating in other active sports. In other cases their goal may be far less physically demanding but still as valued and as important to the individual. It is important

for the prosthetist to recognise that the individual's personal goals may be at a much more basic level of function than the high activity level of others:

Walking is a goal for people. People will often come and say: "I want a leg". "What do you want it for?", "I want to walk", "What is it that you want to walk to do that you can't do now in your wheelchair?". Because a lot of people are in accessible housing and they are looked after ok. "Well, nothing, but I just want to be able to walk". So it's important to people so although I say it's about goals and doing what you did before, there is a fundamental thing about walking that people really, really important that they can do it and just feeling part of society in the way that they did. (Eve 429-435)

The goal of walking and of being able to fit in to society and to fulfil their social roles, as they did prior to amputation, was considered to be a fundamental aspect of personal and social identity. The ability to walk was seen as a basic element in social integration, even if this added little in terms of real function to the individual and, as such, was considered to be a vital part of the role of the device. The heightened concern of the prosthetist to enable social integration by minimising functional difference highlights the perception of the importance of this feature to the prosthetist. Enabling such integration and having a sense of involvement in aiding the individual to be more functionally able and satisfied led to positive reinforcement and job satisfaction for the prosthetists:

But you do get other patients maybe you've brought them in, you've changed their prescription in some way, you've improved their prosthesis in some way and they are now in positively reporting this prosthesis will allow me to do X Y and Z that I couldn't do with my old prosthesis: 'I can now walk round the supermarket: I can now get down on all fours and play with my grandchildren' and all of that type of thing so it can be quite positive. (Chris 49-53)

This positive feedback and the personal gratification the prosthetists received from seeing a patient achieve their own goals of adjustment, particularly when being enabled to function in the way they wanted regardless of the amputation, was welcomed by the prosthetist and viewed as confirmation that they were achieving success in their role.

Both prosthetists and individuals highlight the need for a realistic understanding of technology as a solution to functional and cosmetic difficulties imposed through amputation. Prosthetists perceived a central part of their role as enabling patients to participate in activities that they choose. In most cases prosthetists were open to trying to find technological solutions for patients in order to enable them to achieve these functional goals:

When it comes to things they want to do they will often bring up a topic of things they would like to do. It might be swimming , it might be a particular type of hobby or sports activity and they'll raise the subject or I might have raised the subject if there were areas that they'd like to pursue that they haven't been or things that they'd like to get back into , in which case we would look at that and try and take them in that direction of facilitating that which possibly would mean a different type of prosthesis or a spare prosthesis to allow them to do the additional activities (Steve 70-75)

In using the technology available to them, they are able to satisfy many of the requests of their patients in terms of returning to or initiating particular hobbies or simply improving daily life. While this positive reaction to the needs of the patients was a welcome opportunity for many to improve the experience of their patients, there were also reports of difficulties where the patient's expectations of the available technology were raised beyond that of what was feasibly available. In some extreme situations, patients' expectations of technology showed what the prosthetists considered to be a lack of understanding of the complex nature of the limb loss and rehabilitation:

And the extreme example of that would be the patients who have been on-line or seen something on television. They come in and say to you: "I saw a C-Leg on television, a computerized leg on television or on the internet: I want one of them". A C-Leg is just a prosthetic knee with some microprocessor controls in it. It only walks because of the power the amputee puts into it with their hip musculature but the computerized control stops them from stumbling, helps them to walk downstairs by controlling the rate at which the knee moves but the patient is coming in asking for this as a below the knee amputee and is saying to you: "Would I not be better having my leg chopped off higher up and having one of those knees?" Absolutely not. They have no understanding whatsoever of what that means: to have your own knee versus having a completely artificial knee joint, there's no comparison. In the patient's head: The patient I saw on television walked really well with that computerized knee. (Chris 354-363)

In this situation the expectations of technological advances and solutions are influenced by misinformation from a variety of sources. While this can be partly blamed on such influences, it is also important to recognise the role that the prosthetist and the health service has in educating patients and ensuring a fuller understanding of the possible technological devices available.

Assessment of the requirements of individuals was often reported as being based on their activity prior to the amputation. While prosthetists reported a high level of availability of high-functioning and activity-specific device, individuals were required to demonstrate a need for these devices prior to prescription:

And then there's other, well, you know what teenagers are like. It's a case of: "Yeah, I go out all the time with my friends, running, jumping, playing football", you know, and all this and then they sit on their backside and watch T.V. for twelve hours a day so it's not. It's very difficult to sort of determine all this because a lot of the time patients will tell you

what you want to hear as well and again what I say to my patients is: "If you tell me the truth you'll get the best that we can do for you. If you tell me that you go running and I fit you with a running foot, that will be too stiff and you won't be able to use it". (Mike 582-588)

While this need to assess the individuals' need for a particular type of leg may be valid and necessitated by limited resources, prosthetists must be able to make a reasonable judgement of the actual needs of the individual. In order to prescribe the most useful and practical device they need to have an accurate assessment of their needs and abilities. However, this is also problematic for the patients who are forced to justify their need for any type of non-standard device which may be limiting their ability to live independently, to choose to take up a new hobby or to function in a way that they would have without the amputation.

While successful, enabling use of a device by an individual was reinforcing to the prosthetist, similarly complaints regarding the device and the function which it affords the patient were often frustrating and difficult to contend with:

I've been in several meetings and the patient's saying: "You don't know what you're doing and you're not an amputee and the limb doesn't do this. It doesn't do this; it doesn't do this". And when they give you a big list you feel you are hitting your head against a brick wall sometimes and you say: "Well, we've tried this. We've tried that. We've tried the next thing". I'll be honest from a professional and clinical point of view I can't think of anything else. (Mike 263-267)

For the prosthetists, their part in the process is deemed successful when the patient reports little or no problems and a level of activity which they feel is comparable to their functioning prior to amputation. When this is not the case and patients are reporting problems the prosthetist feels disillusioned and exasperated. While it may be the case that

the level of ability that the patient is seeking is simply not possible, an alternative conclusion may be that prosthetists need to gain a fuller understanding of what the individual is seeking and why they are dissatisfied with the device.

Priorities for prosthesis use

The recognition that each patient has an individual set of priorities and goals and that these should be used to determine prosthetic prescription was underlined by the prosthetists. This extract shows not only this but also the prosthetists' perception that enabling a return to personal functional levels is central to their role:

I think the problem is that every patient that comes in the door is different and what the gold standard for a prosthesis is, is to meet the needs and expectations of that patient so you are right, it's as long as a piece of string. It's as unique as every person in the world. From my point of view it's meeting their needs and goals and expectations whatever they are. (Eve 515-518)

While individual needs and priorities are discussed, the prosthetists themselves also express a set of priorities in their role of prescription and provision of the prosthesis. Functionality is identified as the priority of prosthetists and as such becomes central to their assessment of the patient. As one prosthetist admits, cosmesis is very much an afterthought and even then, only when instigated by the patient:

I think, to be honest, most clinicians, myself included, don't give it a great deal of thought and especially in the early stages until the patient brings it up so you treat, you see the patient and you are literally, and you are assessing the patient in terms of what functional level is this patient expected to achieve? What are their aims and expectations regarding function (...) and then when you get to the fitting appointment you'll say: 'Right, we are going to finish this prosthesis off by putting a foam cover over it' and then, generally speaking you just put a fabric cover over the top to give it a uniform tone which is nothing

like skin tone and you don't give it a second thought from the point of view of "Is this patient likely to be happy with that?" It's not until that patient, a wee bit down the line you can get the patient saying: "isn't there anything better?" (Chris 273-281)

This reliance on the patient to raise any issues with cosmetic appearance and the focus of the prosthetists on function relates to the clinical goal of functional rehabilitation. The lack of systematic assessment and reliance on the individual feeling comfortable and confident enough to raise their own cosmetic concerns may lead to some individuals not having their needs met by the service. Some prosthetists admit that the individuals' needs are not always prioritised, with the focus sometimes being placed on the priorities of the professional. In addition to this, a lack of funding and of development of cosmetic technology often lead to poor cosmetic products on the market or the prosthetist having to choose between function and cosmesis:

The other slight problem with it is that, generally speaking to go for a better cosmetic finish costs more money and depending where you work, money is tight so if you've got a certain amount of money to spend on one particular patient, your prosthetists' default position is to spend a certain amount of money on better kit, better components. The patient might be quite happy walking on a wooden pole as long as it had a cover over it that made it look like the shapeliest leg in the world. There is a trade-off as well between the two but I don't think we ask the patients enough what their preference would be. (Chris 306-312)

Limited funding may have an impact on the ability of the prosthetists to provide a higher level of cosmesis but the lack of interaction with the patients, in terms of their priorities and requirements, is of equal importance. The prosthetists' decisions on how to spend the money available to them should be based on the specific requirements of the patient rather than on the assumptions made by the clinician.

Further assumptions made by the prosthetists seem to centre on the priorities of particular groups of individuals. In terms of the cosmetic appearance of the prosthesis both gender and age were raised as defining factors in what an individual would rank as being important. While these were by no means pervasive opinions across this group, the experience of some led to assumptions based on these groupings:

If I was being pernickety about it you could say that cosmesis, on average, would be more of an issue for ladies than it would be for gents but, having said that, there's plenty of men out there for whom cosmesis is important and that doesn't matter whether they're wearing trousers or not or shorts. They are aware; they want their cosmesis to be nice, to be as good as it possibly can be. On average I would think that cosmesis is slightly a bigger issue for women. (Steve 118-122)

While this prosthetist admits that individuals of both genders would consider cosmesis to be important there is an assumption that this would be more important for women than men. This illustrates that clinical decisions may be influenced by the prosthetists' perceptions or assumptions about particular aspects of an individual. Similarly judgements made based on age could influence clinical decisions:

I think younger kind of teenage to mid-twenty males it's become really important. Not necessarily do they want it to look like a leg but they want it to look l, you know sometimes they just want designs on the socket or a carbon-fibre looking socket or something that looks a bit different so it's not necessarily to look like their own body but they want it to look really cool or really smart or... (John 537-541)

Again, while this may be the view of many individuals, the danger is the assumption of the prosthetists that a certain group of individuals will have this view and prescribe accordingly without considering the view of the individual.

In either case the key issue is involvement of the individual and correct assessment of their priorities rather than provision based on the assumed priorities of the prosthetists.

Individuals' Experience

Expectations of prosthesis use

In the early stages of adjustment to amputation individuals admit to a perception that a prosthetic device will immediately “fix” the problem and allow them to continue living with little or no disruption to their life:

“Yes, but you get those legs and you just walk”, that’s what I remember thinking. That’s what will happen. I don’t think I really realised what a huge impact it would have on my life. (Holly 292-294)

The simplicity of this attitude of prosthesis use reflects the expectations this individual had on entering the process of rehabilitation. The impact on daily life, rather than being minimal, was vast in reality. That her expectations were so at odds with the reality with which she was faced suggests that preparation for prosthesis use was insufficient for her to create a reasonable picture of the challenges which would be presented to her. This suggests that steps to educate individuals of the challenges of prosthesis use and post-amputation rehabilitation are needed from the very early stages of the clinical process in order to correct these naive views.

This lack of preparation for and understanding of the difficult reality of learning to use a prosthetic device was echoed in several other experiences. A sense of urgency in terms of being able to progress quickly is evident with several individuals reporting feelings of frustration in discrepancies between their expectations of time it would take in order to learn to use the device and feel independent and the reality:

December the first it was when I first got my first leg which did help a bit but even getting it then it was hard cause I could only wear it a couple of hours and I just wanted to get it on and get out of there sort of thing eh? (Sam 60-61)

Recovery from amputation was considered to be linked to the use of the prosthesis and that this would provide an immediate solution to impairment. Higher levels of effort and lower functional gains than anticipated led to frustration and disappointment. These expectations of the device reflect a lack of appropriate preparation and understanding prior to amputation. This frustration stems not only from the expectations that they had of their own abilities to recover but also of the perception others may have of their lack of rehabilitation:

so I think there was a lot of frustration at not just getting one of those leg things and walking you know and I think I felt embarrassed because you know people at the time they would say, you know: "You're young, you're fit, you're not overweight, everything's going for you" kind of thing except I couldn't walk, you know and because you get that inactivity it's harder to claw it all back and when you do finally you're over some kind of obstacle. (Holly 534-538)

This lack of progression not only affects her perceptions of self and the image she feels she is portraying to others, but equally unexpected is the impact on future rehabilitation that this lack of activity will have. Coming to terms with the length of time and the level of effort that will be needed to regain a level of recovery which the individual finds acceptable has the potential to impact on the rehabilitation process and should be fully evaluated and considered in the preparation process.

As well as expectations of the use of a prosthetic device and the impact this will have on daily life, individuals also expressed views on expectations of the device itself and of the prescription process. While a level of acceptance of the need for the amputation may have been achieved, the realities of the operation and of the prosthetic device seem to be

something that many are unprepared for. The lack of relevant information and understanding in terms of not only what the operation would entail, but also what this would mean regarding the device was something which was highlighted as potentially problematic:

They decided to take the toes off and I thought “right take the toes off and whatever recovery period...”, but if you’ve never had an amputation, you don’t know what it involves. You’d think, if they cut off half your foot, the other half is still working, and if they give you a transtibial [below knee, mid-calf in this case], you would think “alright, they’ll put a wee dinky wee plastic foot” [laughs] No they don’t, you get [knocks on prosthesis, up to knee] this big thing you know. (Stuart 62-66)

The reality of the process and the impact of prosthesis use could be targeted through pre-amputation preparation and presentation of a more accurate account of amputation and use of a prosthetic device.

While an individual’s expectation of living with amputation and prosthesis use may impact on rehabilitation, it is important to look at the influences on this expectation. Individuals in this study discussed widely the sources from which they gathered information, either actively or indirectly. These ranged from media portrayal of amputation, personal experience and contributions from other parties. The influence that these varying sources have on expectations is reflected in the way in which an individual discusses their own situation and the expectation they have of their own rehabilitation and ability post amputation. The portrayal of particularly high profile cases within the media was seen to influence not only the individual’s perceptions of living with amputation and the capabilities of the prosthetics industry, but also their expectations of themselves post amputation:

I thought I was going to be able to walk the way I used to be able to walk. I think that’s the honest to God truth. I didn’t think about it that much but I just assumed because they could produce something so pretty and, you know, we’ve all seen Heather Mills, the

professional amputee as I call her, we've all seen her and of course she's got that image and, I did, I just thought it can't just all be cosmetic but I very much get the impression that I think it is. (Holly 105-109)

This idea of the “professional amputee”, the highly visible, public portrayal of life after amputation leads to an over-reliance on this as being a reality for all, regardless of the specific situation of the individual in question. Assumptions with regards to the potential outcome of the rehabilitation process, based on such skewed and potentially inappropriate comparisons, can lead to frustrations if the individual finds their own situation different to the reality which they had been led to believe via this media coverage.

In addition to high profile cases such as this in entertainment media coverage, the increased coverage of disabilities in everyday life, particularly with regards to military personnel, was highlighted. Recent increased exposure of military injuries and the publicity surrounding them was emphasised as being, at least partially, responsible for influencing the expectations of those facing amputation in terms of increasing their expectations of the abilities a prosthetic device would afford them:

People's expectations of their limbs have increased tremendously and I think the young people today and actually these young soldiers who are being blown up – they expect to have a running leg and they expect to be running in a matter of weeks because their colleagues are, because it's in the news, because it's on the telly – all these soldiers in the gym with running legs. (Penny 247-261)

This increased awareness and public exposure of amputation and prosthesis use, particularly in terms of the technology and ability this allows, influences the expectations of individuals themselves and of society. The media presents images of amputees who are highly functioning due to their own physical abilities and the technical specifications of their device, which in turn leads to the observing individual assuming that they too will be able to

reach such levels. The comparison is with another amputee, with little or no consideration for the medical or person-specific situation surrounding the amputation and the extent to which such factors can influence their rehabilitation.

In addition to exposure to media representations of amputation and prosthesis use, individuals also reported actively sourcing information, which in turn could have both positive and negative effects on their expectations of prosthetic technology and use. Active internet searching exposes individuals to an array of technological possibilities out-with a context which would enable them to explore whether they were a suitable candidate for that technology. In addition, this comparison focuses on the perceived in-equalities between the services and technological provisions available here with no consideration for differences in healthcare systems or in the practical availability of such products:

And even some of these ones you look at on the internet, in America, power knees and that for walking up stairs normally and all that. Obviously they're robotic sort of things. It'll get better, eh? (Sam 1326-1328)

This individual's assessment of this information leads him to form expectations of the possibilities for improvements in his prosthesis use. While such improvements may be possible technologically they may not be possible for him given his own medical and physical circumstances. Again, the focus is solely on the device and that which it may offer in terms of rehabilitation but without an understanding of contributing aspects of rehabilitation.

While these improvements and technological advances were reported by many as being revolutionary and increasing the satisfaction with their prosthesis and their overall experience, the expectations of potential for technological advances may not be in line with the actual available solutions. Difficulties with other aspects of the devices were often cited as being problematic and in need of attention at the research and development level:

It does seem a bit perverse, in these modern times, that they still make sockets out of rigid plastic. I'm sure if some money was put into R&D you could make a socket, out of some sort of material that takes the shape of your leg each time you wear it. Rather than making a rigid cast, which doesn't allow for the changing shape of your leg, due to things like weight loss/gain or fluid movement etc. They may well have already worked out a way to do this & perhaps the NHS don't have the budget to issue them. But I'm sure there must be away to improve on socket comfort, which would be a massive help to a large number of people.
(Sean, email 216-222)

Individuals expressed frustration at some of the technological difficulties they were experiencing and assumed that these would be able to be rectified at some point in the future with technological advances. In many cases the assumption appeared to be that technology would continue to progress and develop in order to provide prosthetic devices that would be able to offer a level of rehabilitation that was beyond that which is available today. The expectations that technology will continue to develop indefinitely and will continue to provide improvements in ability and function while maintaining a level of positivity suggests a different understanding of the relationship between an individual's medical circumstances and the potential for functional rehabilitation. It does however show the perceptions of the individual that such developments will be forthcoming for him which may in turn lead to dissatisfaction with the limb which he is prescribed if such developments are not forthcoming.

Living with the prosthesis

Negotiating the practicalities of limb loss and adjusting to, or accepting, both enabling and limiting aspects of prosthesis use requires consideration of prosthetic technology. For the most part this technology is seen as providing a solution to the problems posed by amputation but also presents limitations. Individuals' understanding of technology was portrayed in terms of both the solutions that had thus far been provided to them through

technology, and of the advances that they were anticipating in the future. In addition, they also pointed out frustrating aspects of living with a prosthetic device in terms of the limiting or controlling aspects which they had not necessarily appreciated.

While the amputation itself could be categorised as enabling, the use of a prosthetic device was similarly seen as being an enabling entity. The device gives function and ability, which affords an independence that the individuals highly valued. This emphasis on functional ability and the importance it holds to the individuals is echoed throughout their experience, as has been highlighted in terms of personal identity and social experience. The specific ways in which the device enables an individual are of personal relevance and will vary for person to person; however, the unifying theme is that of enabling the return to, or continuation of, a pre-amputation, active existence. For some the aim of prosthesis was to gain basic functions such as self-care and independent living. For others more complex issues, such as returning to work or being able to provide for themselves and their families were a key factor. In each case the individuality of the function which the prosthesis provided was apparent but the unifying factor was that the individual felt that the prosthesis was enabling in a key aspect of their lives. The concept of independence and personal choice appears to be a key factor in what the prosthesis provides for an individual:

I think you forget how much you take for granted, freedom? For when you do get that little bit of independence back you think: 'WOO! I can go and buy a paper if I want to'. I think it goes back to choice again. Do you want to go to Waitrose? Do I want to go to Waitrose? You make up your mind. (Holly 556-559)

The prosthesis also enables function that allows the fulfilment of social roles. This extract explains the importance of the prosthesis in allowing a return to work. This individual not only sees this as fulfilling personal needs and protecting independence but also as a central factor in her definition of playing an active, accepted role in society:

I was desperate to go back to work – I was so bored and I wanted to achieve again and I think this is part of it – you know, mentally, I wanted to be part of the human race again and having the limb enabled me to do that as well. (Penny 91-94)

The isolation which she felt at being unable to work is evident. Not only was this an important part of her own life but was important to her in terms of the role which she plays in a wider society. In this way the prosthesis facilitates, not only a personal achievement, but one which allows integration and adjustment at a wider societal level.

When discussing their progression to date and the aspects of technology that have enabled them, discussions centred around that which had been transformational to them in terms of their ability over and above the basic function of standing and walking. These seemingly small aspects, which made a huge difference to experience, were related to providing a smoother, more comfortable and less invasive device, which integrated more fully into their lives and their expected functioning. Technology which would allow them to walk more easily, to go up and down stairs with a more natural gait and aid them in particular actions such as bathing or swimming, were particularly appreciated. These aspects were all viewed as enabling them to achieve a natural movement and one which allowed them to return to their own personal normality. Improvements in technology were often thought to be revolutionary for individuals in terms of the mobility and function they afforded:

I was a fairly active farmer and because I was active the problems with the limb, you know, it would come off in the field - I would get it stuck in the mud or I would just jump over a gate and it would be left behind and the sores, because of my activities were always a problem, I was always suffering. Then the system radically changed to the Icecast system with a pin on the bottom of the silicone sheet and overnight my ability just changed and I could run - there was no longer this one and a half inch delay when you put your leg up

while the prosthesis caught up with you - it was a real innovation then and that's when I started running. (Tim 44-51)

The level of activity possible with the new system was unexpected as he had assumed that the system he had in place offered him the best solution available. The improvements to his ability impacted not only on his employment but changed his life completely, allowing him to take up running, fundraising and challenging him athletically. The improvements were not only physical but in turn increased his confidence, removed his self-consciousness and allowed him to feel not only comparable to others but to his self-image prior to the amputation:

You get confidence with what you are wearing. You are walking well. You are walking with assurance, jumping over stuff, the fact that it is an artificial limb is negated (....) And then it becomes a plus or a minus and an about-face when you kind of think: I'm in your face. You know: I'm saying It's kind of: "Hey, look at me. I've got this technical stuff on and it's carbon fibre and hey, isn't it smart?" And so it turns around so rather than trying to put this cosmesis on and hide the fact that you are an amputee, you are saying, "hey, bollocks, I'm an amputee and I'm O.K. I don't care cause I'm as good as you". (Tim 161-165)

The advances in technology are so vast in this experience that he reports the fact that he has lost one leg as being irrelevant to his function and ability. The lack of concern with an anatomically correct cosmesis in this extract highlights the importance of function in prosthesis use. The suggestion that the need to hide the amputation is negated by functional achievements emphasises this aspect of integration of prosthesis use into everyday life.

While the majority of individuals expressed gratitude for the abilities that the prosthetic device affords them, there were also limitations and frustrations with the technology. For some this may be the result of their own expectations of what the prosthesis would give them

in terms of function not being satisfied. This may be due to raised expectations of technology or rehabilitation. For others it may be the recognition that the limb will never be as good as their original leg and their attempts to adjust to that reality. The limitations that are imposed by the prosthesis are, for the most part, related to limitations in movement when the limb is unable to be worn due to comfort issues or requires technical attention:

It has been up and down, good days and bad days. Good days and bad bits. I wouldn't really ever say I've had a bad day apart from when I've had, when I'm not wearing the leg or I cannae wear the leg which happens very, very little. It's only usually when it's coming up to time to get a new socket. The socket comes in, it's no fitting. You have the odd day or two. (Sam 1255-1259)

The overwhelming attitude that the experience of prosthesis use is positive and enabling makes it all the more frustrating when limitations are experienced. Individuals come to rely on their limb so much that any time spent without it impacts on their ability to function on a day to day basis. In addition, the realisation that the technology and their amputated limb does have limitations, and that these may not be able to be resolved to their satisfaction, can lead to further exasperation. Where there is a higher impact on life than expected or where function, comfort or ability are not in keeping with the expectations of the individual, this reality is often difficult to contend with:

Mentally I accepted the fact that it had gone. I went to ((hospital name)) I did see people meandering about who had lost both legs and I thought, fine, if they can do it, so can I do it. That was initially. Now time has progressed and whether it's because of the other one or not, it impacted at the beginning but it's impacted on me more because I feel as if I am a fly caught in a spider's web, getting nowhere, struggling, struggling. (Tom 314-317)

The sheer frustration expressed here is due to the difference between what he had expected to be the outcome of prosthesis use and the experience that he is now facing. A

lack of a true appreciation for the potential variation in experience between individuals is evident. This provides a comment on the preparation provided prior to amputation as well as the reliance that individuals place on social comparison in generating their expectations. While limitations caused by the prosthesis may be responsible for interrupting daily life they were also blamed for imposing upon the bigger, more aspirational, personal goals. Often this led to frustration for the individual and required either an abandonment of these ambitions or at least a renegotiation of the reality available to them. This is particularly the case where what they consider to be avoidable drawbacks are imposed; for example, if their prosthesis is badly fitting, or has to be removed for repair. Without a prosthetic device many express feelings of isolation as their ability to function is impaired, which in turn impacts their sense of personal belonging and equality to others:

See when I had to have the leg off like last week ((when prosthetic device was causing pain and had to be removed for repair)) I was probably more down than I've been in ages because I couldn't put it on and that's when you start thinking about "Right I'm no going to sit at the back, look out and watch people walking past" and all that and you just think because I cannae even do that but that doesn't cross my mind when I've got the leg on when I'm out the back doing decking or building benches or anything like that. (Sam 656-661)

The prosthetic device is essential for allowing this individual to feel confident in his functional ability. Without it he struggles to interact and is uncomfortable and unhappy at being limited by the restrictions imposed on him by faulty equipment. The importance of a well-functioning and reliable device and the impact on both psychological and physical aspects of daily life may not be anticipated but for many are intrinsic to the realities of prosthesis use. These difficulties are often encountered and mentioned in terms of the preparation and acceptance needed in order to continue to function as well as possible and reduce restrictions in spite of these limitations:

Unfortunately, we were going off to Italy in a week's time and I knew I couldn't get it mended and I knew my spare leg wasn't as good. Spent the second week using a couple of sticks - that was the sort of thing that happened and you just had to accept it. (Patrick 172-175)

Preparation for such difficulties, through utilising alternative solutions such as a wheelchair or crutches, allows the individual to remain in control and minimise the disruption to their life. However, this is not always either possible or desirable for the individual where the physical problems remove the possibility of using additional support.

In addition to the assumptions and anticipations expressed with regards to technological advances, individuals also discussed their self-management of prosthesis use and often of the device itself. In order to maximise their use of the device and to ensure that it benefits them in the most useful way possible, individuals had found their own ways of managing their use. This may be related to the regularity with which they wore their limb, the times at which they chose not to wear it, or through self-adjustment of the device. In terms of the regularity with which it was worn, individuals are keen to ensure that the limb gives them maximum benefit and comfort at times when they need it. To this end they often chose not to wear it at home or on days where they were not working so as to “save up” hours of wear for when it was unavoidable. While the individuals admitted this may not be the way in which the prosthetists assumed they wore their limb, rather they assumed it would be worn permanently, individuals were aware of prioritising wear according to their needs:

I've been working from home a lot this year. There was one specific area and I was waiting for it to heal and I'll work from home. I won't be on my legs between nine and four o'clock and then when four o'clock comes I've got a few hours' worth of wear do you know what I mean. (Holly 302-304)

This understanding of their own limitations and the way in which they can self-manage technology in order to increase their own functionality shows the acceptance that the individuals have of the role of technology within their lives: as an instrument with which they must work in order to achieve the level of functionality which enables them on a day-to-day basis. The desire to maximise the function of the device in their daily life is apparent, not only in the way in which they choose to use the device, but also in technical modification of their own device rather than reliance on the prosthetists. Some refer to adding or removing socks, adding plasters or foam or even more drastic alterations in order to ensure that it fits exactly to their own identified needs:

You are given your new leg and you walk up and down the parallel bars and you are happy with it and off you go home. Then you come to walk upstairs. Now, no clinic I have ever been to has a set of stairs that you can walk up so what happens is that the back of your socket cuts into the back of your knee. So as I know a little bit about plastics, I take my leg into the garage, take a fret saw to it [laughs] and I took out as much as 25mm, and I got told off very badly! (William 342-347)

While William feels comfortable adapting the device to suit his own needs, he feels that the prosthetists would prefer him not to attempt self-modification in case of damage to the device and the fit that has been achieved. The suggestion that the clinic does not provide a realistic enough environment to truly replicate day-to-day usage is a consideration that may impact upon the ability of the prosthetist to fully satisfy the individual's needs. Consideration of the reasons behind the individuals' desire to self-manage, such as lack of available appointments, difficulties achieving expected levels of functionality and comfort, and a differing understanding of the technical process behind producing the limb, may benefit from review.

Priorities for prosthesis use

When discussing the realities of amputation and prosthesis use, the focus was very much on the priorities of the individual in terms of what they wanted to gain from using a prosthetic device. In terms of the key elements provided by the device the hierarchy of priority was overwhelmingly on function and comfort followed by cosmesis. Having a prosthetic limb which enabled individuals' functionality, and was comfortable enough to wear regularly with little or no interruptions to their day to day life, was essential. While cosmesis was considered to be of importance to some, the majority of individuals expressed this to be a secondary consideration, only once the functional and comfort aspects of the device were satisfactory. Function and comfort were often used in an almost interchangeable way and were considered essential to minimising disruption to everyday life. A device which could be worn with little or no awareness of the wearer was considered to be a successful limb:

Yes, number one has got to be comfort of fit. You know, if you don't know you're wearing it, it's the best leg in the world. (Tim 374-375)

Where comfort and function were successfully integrated they were identified as having the potential to influence how the individuals viewed themselves and their willingness to wear the device. The impact that a badly fitting or uncomfortable device may have on an individual's confidence was highlighted as impacting not only on the wearing of the device itself but also potentially on other choices such as displaying the device in public. If the device was well fitting and comfortable this in turn led to a level of confidence that allowed an individual to consider other aspects of their appearance over and above that of the device itself:

Comfort and function over everything else. Because I think if you had the comfort and the function you'd sort of think "Well, go out and wear that frock" whereas I think at the

moment [while experiencing discomfort and limited use of prosthesis] you are kind of toiling and you're feeling a wee bit uncomfortable and you know that kind of thing. But definitely it's got to be function and comfort. (Holly 596-599)

When the comfort and function are satisfactory to the individual this also impacted on their confidence in themselves and their abilities, resulting in less concerns with regards to their appearance in public or any potential embarrassment that a poorly fitting device may cause. The link between function, self-assurance and public perception was similarly highlighted by another individual. The confidence he felt by being able to “walk tall” and feel less conspicuous in a social setting was vital to him and intrinsically linked to the ability and function that his limb affords:

It's all about confidence and if you are walking tall, you know, you got confidence if you're walking tall then it doesn't really matter. (Tim 393-394)

While function and comfort of the device were prioritised and linked to confident adjustment and acceptance, cosmetic issues were reported as being of less importance, or at least ranked as being prioritised only after function and comfort had been achieved. In most cases, the reality of prosthetic use had led to a lowering of expectation as to the potential for cosmetic appearances of devices. The perception that a prosthetic device would never have the appearance of a human limb led to a disinterest in the appearance of the limb. While a more “normal” appearance for the device would be appreciated, this was considered to be unlikely:

In terms of aesthetic, leg looks pretty rubbish, but not really bothered about that, as wouldn't ever wear shorts now. NHS only offer fairly basic cosmesis, you have to go private to get a "realistic" one like Heather Mills. I don't even have the best NHS cosmesis on mine, as still looks like a false leg. You'd never get one that even looks slightly realistic so not really worth bothering at all. (Sean, email 202-207)

As with many individuals this extract shows a lack of willingness to display the device to others but rather to hide it with clothing. There appears to be a great contrast between those who are willing to display the device and their amputation and those who wish to hide it. In this instance, the individual states that he would not be willing to display his prosthetic device to anyone regardless of its appearance. Others suggest that showing the device is not problematic as long as the device is giving a comparable level of function. In either case, the level of personal priority is clearly important and should be addressed.

In adjusting to the use of a prosthetic device, individuals explain the relationship with their prosthesis in a variety of ways. For some the device, when fitting correctly and allowing them the level of functionality that they desire, is considered part of them. They are as unaware of their prosthesis as they are of their other leg:

I think at the moment sitting here, it's a part of me. When at night time it's through in the living room, it's not part of me so sometimes it is and sometimes it isn't. When I'm actually wearing it, it's just a part of me and I don't think about it anymore than I think about my other leg. (Neil 367-371)

The link between functional satisfaction and the ability of an individual to incorporate that device into their own body image links to the priority of function over cosmesis previously expressed by individuals. When a device is providing the level of function, comfort and ability that they are satisfied with, the device is less noticeable and merges into the experience of their own body and self-image. However, where the device is deemed uncomfortable or difficult to use, the prosthetic is much more troublesome and seen as a mechanical device rather than part of them. In these cases the preference is to remove the leg to feel more like themselves:

I tend to take my leg off if I'm on a long flight. I never take the sleeve off but just that actual thing of taking the leg off just makes you feel a bit human. Whatever anybody says,

just having this attached to your body never feels natural - never, you know. (Gareth 274-275)

That this individual needs to remove the device in order to feel “human” suggests a lack of acceptance of the limb and a lack of satisfaction with the ability it affords, HE is more aware of his amputation and the difficulties this causes particularly in comparison to himself as he was in his non-amputated state and with the able-bodied community.

These priorities of individuals are summed up by one individual who argues for a personal assessment of priority but that in her opinion the key factor is that it must be useful first and foremost:

I think the easy answer is to say it should be whatever the potential user wants, however, we don't live in a dream world so I think it needs to be fit for purpose, whatever the purpose is that the individual needs it for. (Penny 535-541)

While “useful” may mean different things to different people, by far the most important aspect of this is the assessment and involvement of the individuals’ own priorities in the prescription process. Any presumption on the part of the prosthetist as to the needs of an individual may lead to difficulties in adjustment and dissatisfaction with the device and should be avoided.

Chapter summary

An individual’s experience of limb loss appears to be greatly influenced by their ability to integrate the prosthetic device into their daily life in a personally meaningful way. The expectations that an individual has of the device impact on their experience and are also identified by the prosthetists as being influential on the rehabilitation process. Prosthetists perceive an expectation from the individuals that the prosthesis will provide a quick and easy fix to their limb loss but that they have a lack of appreciation of the complex interaction of

issues surrounding amputation and rehabilitation over and above the prescription of a prosthetic device. These are thought to be influenced by the portrayal in the media of high-functioning prosthesis use or from others who lack the professional knowledge to comment. The prosthetists therefore feel that they have a responsibility to “manage” these expectations and to tailor them to a reality which is more in keeping with their professional perceptions. Individuals admit a perception that the prosthesis would be able to “fix” them and allow them to return to their pre-amputation state. They express frustration when this is not the case and seem to have some difficulties appreciating the impact on life of using a prosthetic device. Again this does appear to be influenced by their perceptions of prosthesis use portrayed in the media and often they show little awareness of the differences between them and the high-functioning amputees that are highlighted. While the perceptions of the prosthetists that patients place too high an expectation on the device is in some cases founded, this highlights the need to address these issues at a clinical level and to acknowledge the influence they may be having on the individuals’ experience.

In terms of the integration of the device into daily living, both parties see the prosthesis as enabling and with the goal of returning to a pre-amputation level of activity where possible. However, the prosthetists indicate difficulties in terms of not always being able to meet the individuals’ expectations on these counts or being constrained within the system. They also express some difficulties in contending with patients who express dissatisfaction, often looking to the patient themselves for the source of the problem or to find the solution. Individuals do seem to be aware of the limitations that are placed on them in daily life with prosthesis use, which are mostly related to comfort and unexpected constraints. They seem to be able to find ways around these constraints for themselves although they also express a high level of anticipation of technological advances and solutions which is often unfounded.

Finally the priorities of each party relating to prosthesis use are discussed. For the most part, each party agreed on function as being of the greatest priority. However, in the

prosthetists' experiences, it is revealed that often the patients' view is not always fully considered or may be lost in trade off for the prosthetist-identified priority of function. While this may be constrained by systematic limitations, assumptions made by the prosthetists, based on other individual factors such as age and gender, should be considered for their role in clinical judgements. For the individuals, having a device which enables them, and which is useful and comfortable, was central to their experience. The concept of "useful" is personally specific and should be properly assessed in order to fully enable the individual in their particular circumstances.

Chapter 7: Communication

Introduction

In the previous empirical chapters we have seen how prosthetists and individuals who have lost a limb share their understanding of the experience of amputation and rehabilitation to varying degrees. Issues of differing understanding within this experience often indicate the need for an evaluation of the conflicting perspectives between these two parties. Rehabilitation following amputation takes place with the relationship between prosthetist and individual at its centre. Aspects of this relationship are highlighted as being key components in shaping the experience of amputation and prosthesis use. Interactions between patient and practitioner are the main source of information sharing in this process and have the potential to influence preparation for and adjustment to limb loss. Divergent understandings of the level of such information sharing and understanding between the two groups has the potential to influence this adjustment and the overall rehabilitation experience. Patient involvement in care is also a key feature of these interactions. The understanding of the level of responsibility placed on the individuals within the context of a patient-led interaction varies between prosthetists and individuals. This varied understanding has the potential to impact on the experience of both groups and therefore requires further attention. Constraints and limitations under which the prosthetists must operate are discussed and the potential impact that these have on both the service provided and the experience of the individual are highlighted.

Exploration of the differing systematic expectations of each group begins with a discussion of the process itself and the understanding that each group has of it. Discrepancies in these experiences and a lack of shared understanding could lead to dissatisfaction and frustration for both parties. Similarly the expectations that each party has of the outcomes of rehabilitation, the way in which these are communicated and the potential

impact of incongruity is discussed. The perceptions of the NHS as being below par in comparison to private or military care seem to reflect the prior assumptions of individuals although this discrepancy is debated by the prosthetists.

Finally, the role of the prosthetist within the relationship and the rehabilitation process is discussed. The prosthetists view themselves as playing a complex, multifunctional role encompassing, not only technical expertise, but also social and moral support with ad hoc consideration of psychological issues. For the individual participants however, the prosthetists role comprised mainly of technical skills and provision of an appropriate device. Any additional support was found from a variety of other sources, both clinical and personal. Prosthetists highlighted the ambiguity of their role and the lack of psychological support services to which they could turn if needed. This posed a difficulty for prosthetists and should be considered as a potential area for further investigation.

Prosthetists' Experience

Prosthetist and patient interactions

Interactions between the patient and the prosthetist are key to the rehabilitation experience. In the time immediately prior to amputation and particularly in the initial stages of rehabilitation post amputation, the understanding that the individual has of their medical situation is highlighted as being of vast importance by the prosthetists. When discussing this understanding, the assertion that it should include a “realistic” perspective is often made. The discussion of the concept of “reality” encapsulates an appreciation of the limitation and challenges that the prosthetists assume are inevitable in amputation and prosthesis use. From the onset they see the acceptance of such limitations as being essential to the individuals’ rehabilitation. As such, discussions of such issues are seen as being central to the interactions between prosthetists and their patients as well as wider support networks, both professional and personal:

There's no choice, so I wouldn't say that the patients are...they're realistic for a start. Those particular patients are realistic because they've had those discussions with the surgical team, they'll have had discussions with their family, perhaps a counsellor would be involved at that stage, those kinds of things, so they're very kind of matter of fact: "This is what's happened. This is the situation I'm in and this is kind of like my only option to benefit myself". (Mike 90-94)

The prosthetists' goal, and that of the wider medical team, is to create a situation whereby, through effective communication, the individuals comes to think of themselves as part of the decision making process. As such the patient is thought to feel satisfied with this decision and ultimately to accept the medical plan as it is presented. The prosthetists relate their experience and professional understanding of what they consider to be the "reality" of limb loss and prosthesis use. This includes their perception of an unavoidable level of limitations and potential difficulties. In discussions of patients' "realistic" views, there appears to be an assumption that patients not only recognise this series of circumstances but that they also accept them both, practically and emotionally, prior to amputation.

The prosthetists emphasise the importance of a patient-led discussion and service in which the patients' views are foremost in their concerns as practitioners and should be central to the prescription process:

There's no point us saying: "It should do this, It should do" that if that's not what people are interested in. Everybody that comes in the door has the right to have somebody listen to what's important to them and do their best to provide that rather than a set standard. (Eve 524-527)

The emphasis here is on individuality and ensuring that not only is the patient given the opportunity to express their own needs but that it is this unique blend of individual factors that will determine the clinical outcome. The prosthetists present a desire to create a system

where their ability to communicate with the patient, and to identify and act upon their own unique set of requirements, is central to their clinical process. However, in describing this process they acknowledge the limitations imposed on them, not only by the system within which they operate, but also the practicalities of the technology available to them. These constraints on their clinical practice present the prosthetists with a variety of issues of which the patient may often be unaware. In describing their experiences of attempting to meet the needs of the patients, prosthetists admit that often they must be mindful of systematic concerns, such as funding availability or time constraints, and that these play a large part in their decision-making process with regards to prescription:

I would say it's kind of like a double-edged sword, to be honest, because on the one hand it's a case of: I know this patient really well and I know this would benefit them but, they don't really need it, they're getting by fine without it. Sometimes there's a kind of cash, a kind of monetary constraint, often a lot of the time it's not though. It's often a case of they're getting on fine without it. If it's not broke, don't fix it. You don't want to kind of, not create work for yourself, but you don't want to, you know this patient's been fantastically happy with this limb for say two years. You don't want to put something, say a new foot or a new knee on which would compromise that because at the end of the day a lot of the time the patients will have jobs, family, children (...) (Mike 194-201)

This suggests that, despite knowledge that there may be a more advanced technical device available, clinical decisions may be made without fully informing or including the patient. While this may ultimately be the clinical decision the prosthetists feel is most beneficial to the patient, it is also determined by additional, non-clinical factors and often without full disclosure of this reasoning. While the prosthetists discuss their priority as being entirely “patient-led”, the admittance that additional factors are also implicated in their decision-making process suggests that this is not necessarily always the case.

While prosthetists report their determination to create a patient-led service, it appears that, in some cases, rather than encouraging and enabling the patient, a certain onus is put on to the patient to take charge of their care rather than relying on the prosthetist to lead it:

Is there anything that would make life easier? So that's what I mean, its patient focused. I don't call people in to say: I think that foot would be good for you. I want them to approach me. And so it really is, I like to think that the emphasis is on the patient to tell me how they would like to proceed rather than me forcing them. (Mike 54-57)

In this case the prosthetist portrays this patient involvement as being a positive attribute of the care process; however, a reliance on, or over emphasis of patient input may remove the responsibility of the prosthetist to communicate effectively with the patient and to use their own skills to gain a greater understanding of the needs of the patient. Rather, the prosthetist assumes that the patient will have the ability and knowledge to efficiently convey their needs to their prosthetist. In addition while the prosthetists want the patients to be proactive in sharing their priorities with them, the patient may not always have an awareness of this. The patients may assume that the prosthetist will always provide the most suitable solution regardless of their additional input and therefore not engage in this proactive way. While the emphasis on patient-led service may be somewhat misbalanced in the perceptions of some clinicians, others were aware of their need to hone the skills required to encourage patients to reveal information without placing the responsibility solely on them:

the more patients you see the easier it becomes if you like, the more you're able to have a conversation without having to ask questions directly. You have a conversation and glean what information you need and that makes them feel more at ease because it doesn't make them feel like they're being interviewed or anything like that and it doesn't make them feel like they're under pressure to answer questions and again, it's just part of it is this rapport. (John 167-172)

A positive awareness of the role of the prosthetist in the process of effective communication and in the need for them to display particular skills and abilities in their patient interactions is commendable. The relaxed and informal air within the relationship is thought to not only impact on how the prosthetists are viewed personally, but to also impact on the outcomes of rehabilitation. The rapport which they develop with their patients is viewed as essential to ensuring that the patient is satisfied with the outcome of the service. This in turn is thought to benefit the prosthetist as well as the patient:

Well, it is a responsibility and I'd like to think that it's all part of the training, it's all part of the day to day job and I think that's the most important part of the chemistry if you like (...) because you can have the best-fitting leg in the world and everything can be absolutely great but if you don't get on with the patient then you will probably never actually get the benefit of it, the patient won't get the benefit of it and you won't get the benefit of them saying "This is great, see you in six months" kind of thing. (John 148-149)

The prosthetists report a responsibility to build an effective relationship with their patients. They consider this to be central to their role and essential for effective rehabilitation. As such, the prosthetists maintain that an individual's rehabilitation may be hindered by a lack of rapport or ineffective relationship with their clinician. It seems counter intuitive to suggest that if an individual has been prescribed "the best fitting leg in the world" that it would not be useful to them despite the relationship with the prosthetist. This may suggest that the prosthetists are looking for additionally impacting factors if the process does not have an outcome that they deem satisfactory. In situations where the prosthetist feels the interaction is less than optimum and the patient is expressing low levels of satisfaction with the limb, prosthetists can feel despondent at their own lack of success as well as the lack of successful outcome for the patient. In such cases prosthetists often insinuate that technical difficulties are the result of psychological issues impacting on the patient and are therefore beyond their control:

They're not getting on well: "there must be something wrong with the leg". I'll do this and I'll do that and I'll fix it because that's what we like to do and of course we can't fix it and we get more and more kind of despondent that we can't solve these people's problems and you know, it's only after a long time of that that you actually think:" Is there something else? Is it not just the limb? Is there something else going on?"(...) you know it's really upsetting when people are struggling and struggling and not getting anywhere. (Eve 109-116)

The prosthetists have their own expectations of how an individual will progress in their rehabilitation. Where the individual does not meet these, the prosthetists look elsewhere for reasons, in part to allay the frustrations that they experience and those which are perceived from the patients. This may be the result of the prosthetists' expectations being misaligned with the ability of the patient or in fact with the level of technical attainment that the patient is looking for. In addition, assumptions regarding the impact of psychological issues may reflect a lack of expertise on the part of the prosthetists to correctly identify and contend with such concerns. A lack of initial and continuing effective communication regarding the process and the device itself can lead frustration for the patient and the prosthetist when issues are not resolved in a satisfactory manner or where the patients' understanding does not meet with what the prosthetists think they can reasonably expect to achieve. Assessing and understanding the needs and abilities of an individual and tailoring the process to suit them is important to the prosthetist, but they also maintain that this must be done within the realms of what they deem to be reasonably achievable and available.

Expectations of the system

In aiming to provide the best possible service to their patients, prosthetists perceive a certain level of expectation from the patients in terms of the process into which they are entering and the ideal outcome that they envisage. This included the expectation of the NHS as a whole, the particular aspects of the prosthetic department and of the prosthetists

themselves. For their part, the prosthetists also held their own perceptions of the process and of the interaction and output that they felt it was reasonable to expect. Frustration at the complex difficulties inherent in fitting the device are reported by both parties; both expect a forward momentum but the difficulties encountered when the understanding of this process is not shared is apparent. For some prosthetists this was perceived in terms of a machine-like efficiency that the patients were expecting of their over-all experience:

((While describing how he feels some patients see the rehabilitation process)) *Yes, as the prosthetist as one stage in the process. So the physio will be one step of the process, the O.T., the nursing staff, the doctor or the consultant. The patient's family is also included in that because everything's taken into account and it's almost like they go in at the beginning and it's almost like a machine and there's big cogs in the machine and they go in the machine and they go through the mill and at the end out they pop, you know, a rehabilitated person. It's not like that. (Mike 19-23)*

The simplistic nature of this description suggests that prosthetists do not consider patients as being fully aware of the intricate and multifaceted nature of the rehabilitation process. While the prosthetists think that patients expect the process to be simple and straightforward, the prosthetists themselves are of the opinion that it is a far more complex process. Additional encounters of such a simplistic attitude lead the prosthetists into feeling that they have a responsibility, along with other health professionals, to instil in the patients a more “realistic” awareness of the rehabilitation process:

It sounds as if you are holding them back but you're just trying to get the realisation that, with the doctors, yourself, with the physios and the OT's all together to try and let them know that what you are going to do for them is the best you can do for them and it's completely varied with patients. It depends who they are and what the cause of their amputation is but it may be the case of trying to put the reins on them a little bit and say: you

know, this may have been what you were like twenty years ago before your ill health kicked in and that sort of thing so a lot of it is the realization of it all. (John 17-23)

The strategy portrayed here is one of multidisciplinary team working but with the shared goal of creating an understanding of the patient that is more in line with the “reality” that the prosthetists and other health care professionals are aware of, considering health, systematic and technological limitations. The potential discrepancy between what the prosthetists consider to be realistic and the expectations of the patient forms a basis for one of the major self-identified roles of the prosthetists. They see themselves as having the key role of negotiating the expectations of the individual and tailoring them to be in line with a service which they feel able to provide. For the prosthetists, the difficulty lies in being able to achieve a balance between what they as clinicians can reasonably hope to provide within the constraints of the medical and practical situation of the patient, while maintaining a level of rehabilitation with which the individual can be satisfied.

Having an awareness of the impact that limb loss may have on the patient and the difficulties that may be experienced if the patient struggles to cope with this adjustment is an important aspect of managing their expectations. As with the previous excerpt, being aware of the way in which this is communicated and the potential for discrepancies between the patients’ views and that of the reality which the prosthetist has to present is of the upmost importance. Prosthetists present this “expectation management” as being central to their role, ensuring that the patients accept the view of the prosthetist as opposed to the purely patient-led approach that was previously discussed. The prosthetists have to find a balance between making patients aware of their own limiting factors, which patients themselves may not be fully aware of, and continuing to enable patients to the best of their ability. Often this involves highlighting issues which the patient appears to have overlooked:

You just have to be realistic about it and there is a bit of mollycoddling and a bit of hand holding involved but it's a case of: "I'm sorry to be the one to tell you this but there is an age factor here, there's a medical factor. You've got high blood pressure, you've got – there's underlying conditions". (Mike 371-373)

Prosthetists see themselves as taking on a role of communication and patient engagement that goes beyond that of the technical aspects of the device. While again the prosthetists view this as a positive and essential role, this extract in particular highlights difficulties encountered following variation in understanding of the circumstances. The prosthetists view it as a difficult but essential ask to make patients aware of their own limiting factors and the impact that these may have on their successful prosthesis use. The prosthetists must negotiate this carefully, highlighting such aspects to the patients but without the imposition of their own assumptions with regards to the patients' abilities and priorities. This would have implications for clinical practice particularly with regards to vocational skills training for the prosthetists.

In explaining their view of the "reality" of limb loss and prosthesis use, prosthetists described their own perceptions of the system within which they work and the difficulties they have in overcoming some of what they see as misconceptions, particularly with regards to the limitations of the NHS and the impact that this may have on patient care:

It is a perception for some that the NHS is strapped for cash and struggling and failing and if only I went private I would get something better which is actually not the case. Certainly up till now in terms of funding I can give out what I feel. If somebody comes in and they need something for something, as long as I can show that they need it, they don't just fancy it because it's hot off the press, then they can have it. (Eve 302-306)

Again, while the prosthetists attempt to protect the view that their care is entirely patient driven and is unlimited, this excerpt clearly shows that even this has limitations as the patient

themselves must prove the need for a particular item before it can be provided. The inconsistency of this excerpt in which the prosthetist protests at the misperceptions of the perceived limitations of the NHS while at the same time quantifying the criteria that must be met in order for a prescription to be made is reflective of the conditions in which they operate. This prosthetists claims that patients will always be able to get the same, personally suitable, equipment through the NHS as they would through private healthcare. However this prescription will be determined by both clinical judgment of need as well as the ability of the patient to prove their need. The prosthetists hold their profession and the NHS in high esteem and their intention is to provide the best possible care for their patients; however, the nature of the system and the constraints placed upon them must be recognised.

In addition to discussions of the NHS and the opinions of the level of care which is provided, prosthetists also discuss frustrations in terms of the expectations which they perceive from the individuals, with regards to the frontline service from the prosthetists themselves. Some of this frustration stems from the difficulties that the prosthetists have in meeting demands of the patients for timely treatment and in response to complaints of delays in completing manufacturing and fitting of the device. Many of these frustrations stem from prosthetists feeling that patients have little appreciation for the complex manufacturing process involved in limb provision. This may result in complaints from patients that the process is taking too long and in some cases the prosthetists feel a lack of appreciation for the difficult task that they have in prescribing and manufacturing the limb:

So the patient only sees either end of that and they just think it's a case of: cast, limb and it just comes out of the other end of the machine like that and then you have to fit it and make sure the patient's happy with it and we're well trained and we're specific in that and we actually make it look easy. You know, it's a four year degree course, it's not, they don't just take anybody off the street. (Mike 300-304)

Not only do the prosthetists feel the need for a recognition at the level of professional service they are providing but also that the individuals need to be educated in the process, particularly with regards to the multiple levels of manufacturing that are undertaken in order to provide the limb. While this focuses on the prosthetists' perceptions of the process and their role within it, they fail to address the reasons for the individuals' complaints: for example, the difficulties faced by an individual who has a lengthy wait for a device and the impact that this may be having on their life. This aspect of service expectation is discussed in detail in the individuals' experience section of this chapter. In addition to the expectation of the system, the prosthetists themselves were considerate of their own role within this process. Their view of the part they have to play in the rehabilitation of these individuals was complex and in some ways problematic for them to negotiate. The differing views of the role of the prosthetist within this clinical relationship forms the basis for the final theme within this chapter.

Role of the prosthetist

The relationship between a prosthetist and a patient was regarded as being one which often took on more than a clinical role. Where a lack of social support was identified as being of concern, professional support was considered to be a viable alternative albeit with limitations. Even where individuals had appropriate social support at home, the prosthetists saw themselves as being a key part of the support network, often referring to the relationship in a personal and informal way. This emphasises the interpersonal aspects of good relationships:

Some patients will literally come in and the first thing you say to them is not 'Hello Mrs Smith How are you getting on today' and 'What's wrong with your prosthesis?' it's 'Hi Mary How are the grandkids and how was your holiday last month?' and things like that because you know them so well, you build a rapport with them. (Chris 22-25)

The prosthetists in this study all identify effective communication as a key component of their part in the rehabilitation process. They recognise good communication skills as being central to enabling them to build a successful and mutually beneficial relationship with their patients. A “good” relationship is defined as consisting of high levels of trust and often an informal, friendship like connection. For them, they perceive the benefits of such a relationship as including open discussion of the needs of the patient and the creation of an atmosphere in which the patient feels satisfied that they are involved in the process:

if they turn round and say: Well, it's just nice that you've listened to me, then that to me is the most important thing because one, it builds up that rapport that we spoke about and two, it shows that we're not just busy clinicians that are running about trying to put artificial limbs on people we are there to try and listen as best we can. (John 476-479)

The desire to portray an empathetic, caring professional role is one which was shared throughout discussions with the prosthetists. For the most part they are keen to ensure that the patients feel happy with the service that they receive and, personally, the prosthetists want to be viewed as friendly, approachable, helpful individuals. While this open and comfortable relationship is portrayed as important for creating a trusting atmosphere, the dual benefit of this relationship should be considered. In creating this relationship, the prosthetists are keen to encourage an atmosphere in which they are able to implement the care plan that they have determined is best for the patient. This may not always include the explicit involvement of the patient but rather the patients' acceptance of the prosthetists' judgement:

We work with the same patient for a number of years and it's important for us to have a good close relationship, one of trust, but also one of reliability that the patient can rely on you to do your job and to do it effectively and that you have their interests at heart and so that takes a lot of time to build up. (Mike 57-62)

In this situation the relationship basis is for the patient to trust the prosthetist and allow the prosthetists to “do their job”. That is not to say however that this may not be the best situation for the patient but more that the interest lays in the prosthetist’s interpretation of the need for a supported trusted environment so they, as clinician, may be able to implement his defined care plan. The emphasis on an empathetic, care giving role builds the case for the prosthetists viewing their role as being more complex than that of simply manufacturing and provision of the technical device. It does however emphasise that a well developed relationship is facilitative of the process. The particular content of this process in order to ensure an obvious involvement of the patient rather than simple implementation of prosthetist identified priorities may be needed.

Additional roles beyond that of technical elements were identified throughout the rehabilitation process which adds to the complexities of the prosthetists’ position. Prosthetists perceived their role as necessitating consideration of, not only the patient, but also the greater context in which they live when determining their clinical course. Rehabilitation is considered a long term process that they are likely to be involved in as a clinical practitioner for a number of years. This may raise additional, non-physical and often more personal concerns from the patient, which become part of the clinical discussion. Again this emphasises the importance of the relationship between the two parties:

They might tell you things that they haven’t said to anybody else and then that’s other things that you have to deal with as well so, it certainly isn’t just about giving them a leg and then discharging them. There’s no such thing as discharging with prosthetics unless they decide they don’t want to carry on wearing a limb so the care is there for as long as the clinician or the patient’s there. (John 181-185)

The rehabilitation process is not limited to the physical aspects of the patient themselves. Often psychological or social issues were identified as important. Prosthetists admitted to a

lack of preparation and confidence in being able to address all of these issues but, nevertheless considered it to be part of their role. While this was not necessarily formal, the long-term relationship which developed with patients meant that it grew organically to be a part of it. As a result they felt they needed to have the skills to facilitate the patient in terms of goal setting, encouraging positivity and recognising the need to contend with psychological as well as physical issues. However, concerns were raised at the lack of training and expertise within the prosthetic field to adequately address such psychological issues should they arise. While dedicated psychological support would be desirable, it is often not available at most centres. Psychological issues are therefore often dealt with in an ad hoc and unskilled manner by the prosthetists who recognise the need to address such issues but also their own inadequacies within the area. There appears to be some confusion over their role, with prosthetists arguing that these aspects are inevitably raised and they do deal with them as best they can; however' ultimately this is not part of their role. If they are to be included in their role then better training is needed to allow them to do this systematically:

Although we're there in a sort of supportive role and we do talk to them and try and empathise with patients, I think that prosthetists are pretty poorly trained in that funnily enough. Yet, I think that, and this is only my own opinion, that the type of person that does this kind of profession is someone that is kind of maybe a caring, listening individual (...) I think it's missing from our training although we're putting more in but that's not really our role. Our role has really been the physical enablers, if you like. (James 134-143)

The prosthetists find it difficult to address the psychological issues that they encounter; however, they recognise that such issues do arise and are of the opinion that they may interrupt or interfere with the physical rehabilitation of these individuals. While the medical and rehabilitation team at the majority of hospitals appears to be well equipped, there is a distinct lack of psychological input at any level, particularly in Scotland where the majority of the prosthetists in this sample were based. This led to a concern from the prosthetists that

they may not be providing the best care possible to their patients and may be lacking in a specific and vital area of support and expertise. This feeling of being ill-prepared to contend with psychological problems or having a responsibility to engage with patients on a psychological level causes concern for several prosthetists. While there is an awareness of this potential impact, there is a real apprehension for those patients with whom they are unable to engage and for whom these issues may become overwhelming. With a lack of structured, formal support from within the rehabilitation service this causes concern that patients may not be receiving the help they need. In many cases the onus is on the patient to contact their GP directly and recognise their own need for additional support which, in this prosthetist's experience, is unlikely to happen leaving the patient isolated and unsupported, again putting more pressure on to the prosthetist to fulfil this ad hoc role:

there are those kind of people who don't engage. You know they're not going to turn round to their G.P. and say: "You know, I'm feeling really depressed" . They're not going to do that. They need us I think to try and step in a little bit (...) they're going to struggle too much and these are kind of the older gentlemen who don't like taking tablets, they don't like to bother people, but you know that they're suffering from depression and anxiety and they haven't been out the house for a few months and again we get a lot of their problems because they literally haven't anybody else to talk to. (Eve 357-364)

The idea of needing someone to "step in" here suggests the responsibility that the prosthetists feel to discuss such issues with them or to encourage them to utilise the support available to them through other health channels such as their GP. Again this makes the point of the perceived missing link in their multidisciplinary chain. While the prosthetists feel that such issues shouldn't be part of their role and subsequently feel inadequately prepared for such a position, they ascertain that they are faced with such issues and inevitably are being forced to address them.

Additional concerns were raised with regards to the perceptions of psychological issues and psychological care provision as being somewhat stigmatised due to the lack of integration between prosthetic and psychological care. Again, the prosthetists feel they are fulfilling a role which goes beyond their job description which needs to be addressed at a systematic level:

I think there's a real gap in our team because we've got team members to cover every aspect from housing and toilet adaptations to all the physical things , physios and doctors and nurses but there's a huge area missing I think not having any help for their mental health. I think it could be a real help if they were just part of the team so that everybody who came through the door saw the physio, the O.T., the doctor, the nurse and the mental health professional in whatever capacity that would be and it's just another person there so that would take away any kind of: "Oh, they think you're not coping. They think you're mental that you have to go and see this person", if they were just one of them. (Eve 222-229)

This discussion of the inclusion of psychological care in the multidisciplinary team suggests the importance which the prosthetists attach to such concerns but also underline their own disquiet at having to integrate psychological support into their role. The major difficulties seem to revolve around their concerns at a lack of training and the classification of what is or isn't part of their job. While they see physical aspect of amputation and the provision of an enabling device as being clearly their role, they are far less certain of their position with regards to such psychological support issues, however very much ascertain that such aspects are being undertaken despite this. This negotiation of professional roles is something which seems to be of great concern to the prosthetists and offers further suggestion for considerations within clinical practice.

Individuals' Experience

Prosthetist and patient interactions

Interactions between the prosthetist and the individual form a vital element of the individuals' experiences of limb loss and prosthesis use. For patients, these interactions are primarily important for receiving and understanding information and with regard to the input which they have in the process. Initial interactions inevitably revolve around the process of amputation itself, the reasoning and the potential impact which this may have on their lives. The level of understanding which they have of this process and the way in which information is shared could dramatically affect their experience. Reasons for amputation can be broadly divided into 3 categories: traumatic, planned, due to potentially fatal disease, or elective, where the individual's daily life is being unacceptably hindered. In each of these cases there are differences in the opportunity to prepare the patient for the potential need for an amputation and in the expected impact of this amputation. The experiences of the individuals' however, suggest that often a full understanding of the situation is not realised, with examples in all case types:

((Following planned operation to unblock arteries in leg)) *Amputation had never been mentioned. I went into theatre at 8.30 on the Saturday morning (...) I came to in intensive care and a female doctor came and held my hand and said "oh ((name)) you're awake, I've got some bad news, unfortunately you've lost a leg". I remember saying, "you've got the wrong person". She said no and my wife said, "it's true" - I thought "Bloody Hell!" So, that was that. (Andy 43-47)*

In this case the severity of the circumstances surrounding the operation and health issues was not appreciated prior to amputation. Similarly, in circumstances where the amputation is a secondary result of an additional diagnosis, the level of information that the patient has to digest is likely to complicate their understanding of all issues:

I think the first week between the first time I went was sort of nothing because I never knew...the amputation, the idea of that never even came into my head. To be honest I was thinking: God, I could to be getting told I've got a month to live and that was basically what was scaring me so nothing else came into it. (Sam 816-819)

In such circumstances, the level of communication from health care staff is all the more vital in ensuring that the patient is fully aware of the planned procedures or the likelihood for a different outcome depending on circumstances that develop throughout the process.

Where individuals reported an acceptance of the need for the amputation there was often a realisation that the procedure was necessary, either in order to save their life or because their physical difficulties have become too severe to contend with. In describing their acceptance of the amputation, often their interactions with health professionals are discussed. Individuals use these interactions as an example of the way in which they came to the conclusion that the amputation was the right one. This action of acceptance is described in terms of their personal decision and choice with regards to the operation, but in most cases this choice is rather more an acceptance of the inevitable either because their life was unbearable as it was or with the only non-viable alternative open to them being death:

Yes, you have to be realistic about it. I mean, what are you going to do, are you just going to die - be totally poisoned by this and you can't shut your eyes to it, I think I was educated enough to understand that. (Gareth 446-448)

The described acceptance here leans more towards resignation that the amputation was inevitable rather than specific involvement in the process leading up to it and an active decision on their part. Being “realistic” in this instance suggests an acceptance of inevitability rather than active, informed decision making. Similarly, this resignation as to the practical need for the operation does not necessarily suggest an emotional acceptance or understanding of the outcome of amputation.

Issues with communication were also raised in terms of the preparation not only for the need for the amputation but also in terms of long-term guidance as to what to expect from life after amputation and using the prosthetic device:

I think that the number one aim was to get rid of the pain and the kind of problems that I had and to be honest, things have changed a lot now, I recognise that because I'm involved ((as peer support visitor)), but the information on how it might have been and was going to be as an amputee was very poor in those days. (Tim 275-277)

The focus of the patient and of the professional communication here was the reason for the amputation and the immediate benefits that could be expected from the removal of the damaged and problematic limb. This information does not appear to encompass the impact on life of the amputation or the long-term issues that may be encountered. This perception was shared by others in the post-operative stages who were aware of a lack of information given beyond that which is immediately relevant to the process. While in the early stages of rehabilitation, individuals expressed a frustration at the focus of the healthcare team and the limited information they were offered in terms of long-term prognosis:

But I think once you've had your limb off in that period before you go for the limb fitting, I don't think there is an awful lot of explaining what might be going on. I think it's just - right we'll keep you mobile - we'll get you down to the gym to do your arm exercises and walk the bar - no I don't think there is time spent. (Gayle 503-507)

Limited appropriate information to prepare in a realistic manner and an awareness of what to expect from limb loss and prosthesis use can lead to difficulties in adjustment for individuals. In these instances, individuals look to alternative sources for information and begin to speculate as to how they may react to amputation and what their life may be like. This in itself can be problematic as often the examples that the patients look to are not comparable to their own circumstances and can create a negative perception. In this

example, the sight of a group of elderly patients in the rehabilitation ward and information found on the internet presented a far worse scenario to this individual than he was prepared for. Due to a lack of additional, practical information from the healthcare team, he finds information for himself, which in turn leads to a negative perception of amputation and gives him a negative start to his experience:

That put me off, seeing them and if things were different from what I thought they were going to be but I don't think there was really anything that I could have done, I maybe even looked too much into it at that stage and made it be worse for me rather than just kind of going in almost blind and just seeing where we can go with it kind of thing. (Sam 895-899)

While realistic and practical information would be useful in some cases and allow for preparation prior to and post amputation, this opinion that some individuals may cope better with less preparation was also expressed. The reason for this involves the perception that some of the potentially more negative aspects of limb loss and rehabilitation may be difficult to contend with. Too much information detailing all possibilities and challenges that the individual may face could in itself be traumatic and place the individual at a disadvantage. In addition some individuals are of the opinion that due to the individualistic and complex nature of amputation and rehabilitation, often exact details are not known and therefore the professionals should carefully assess what information they can confidently share with the patients:

I think people are awful careful what they say to you when you're first an amputee and I think that that's quite right, you know. I used to, I mean just say for example, I used to say: "Nobody's telling me how long I'm going to be in the hospital". You know, of course, nobody knew. (Holly 632-634)

These differing attitudes to information, with limited information seen as being negative on one hand and protective on the other poses a difficulty as each individual will have their

own views on which they feel will be more beneficial to them. This underlines the need for timely information to be available and for the professionals to have a greater understanding of the needs of each individual in order to support them in the way which is most appropriate for them. This level of communication was appreciated, particularly by those individuals who felt that a true understanding of life as an amputee cannot be comprehended by someone who has not experienced it themselves:

As I say, unless you've worn one of these, you are not 100% certain how it feels. So any of these hospitals that you ((the researcher)) go to and your brother ((a prosthetist)), tell him, until he wears one [pause] they can't understand. (Stuart 723-725)

The involvement and contribution of patients to the care process is considered to be important to individuals who appreciated an open forum in which they could ask questions and raise concerns regarding their care and be reassured that they would be recognised. Feeling able to bring particular requests to the prosthetist and feel that they would listen and act upon these was considered to be central to a good service. However, in many instances the requirement to prove the need for a particular piece of equipment or to provide evidence for its worth was felt. This may be the case for new technology which an individual has become aware of and feels may be beneficial to them or help with a difficulty which they are having. One participant describes the presentation of such information to the prosthetic team in an attempt to argue the case for her being prescribed this:

So I went on it and I looked at it and I thought: Oh, Yes. I was going over to the Astley for something so I put together a sort of Dragon's Den speech and said: I want the Echelon foot because...and sort of read it all off and they asked me to attend the clinic because obviously all these things need the Heads of Department and things and they said: Jane, we're not trying to put you off but that foot is made for a grown man to wear (...) and instead of giving me the Echelon foot what they did across there ((rehabilitation centre

name)) was give me this shock absorber here which I haven't had before (...) it's made a big difference in comfort and that's why I can't have my leg clad as it moves up and down. (Holly 116-131)

While the end result of this interaction is the prescription of a device which the individual is satisfied with, the need for her to present the information to the team in such a way rather than feeling able to have an open and frank discussion with them in a normal clinic setting is indicative of the control issues discussed in the prosthetists' experiences of patient interactions. Ultimately the prosthetists here are in control of the situation leading to this individual taking such drastic measures to have her opinions considered. A secondary issue here is the lack of provision of this preferred device in the first instance. This was a situation that was noted by several participants who, rather than appreciating what the prosthetists consider to be a patient-led service, were frustrated at the lack of proactive service being offered to them:

I've really had to fight to get decent legs made & ended up telling them what I think they should do rather than vice versa. It's been really quite draining, and if it wasn't for the fact that I'd previously had good legs, I would have given up & just ended up with really painful legs & a much lower quality of life. (Sean, email 178-182)

This again suggests that the patients do not feel as intrinsically involved in the prescription process as they would like to be. The assertion that individuals must enter into a confrontation with the prosthetists in order to receive the device that they are happy with is again reflective of control issues within this interaction. The implications here for clinical service are that those who are not willing to argue their case or for whom the process is too arduous may ultimately end up with a less than satisfactory, or in fact potentially damaging, experience.

The pressure on patients to lead the interaction was felt negatively by other participants in whose experience the prosthetists were not as reliable or as forthcoming as they would like them to be. Again the onus is on the patient to ensure that the interaction and process progresses as they want it too. This perception was frustrating for individuals who felt that, without their action and continual pressure, the prosthetist would provide a service below that which they were happy with:

But then I'm a 100 per cent, he might totally prove me wrong when I go back and he'll say here's this thing Ta Da! But I'm 90 per cent sure that if I don't mention that again it'll not get mentioned again. It's just its easy when you are face to face and things are getting spoken about, it's easy just to say this and that and the next thing, I just think maybe it's too easy (Interviewer: "so the follow up maybe isn't there?") Aye, they would let it go if you never kind of pushed the issue kind of thing. (Sam 425-430)

There appears to be a perception among the individuals that while the prosthetists are willing to provide a standard leg for everyone, anything over and above that must be explicitly proven to be needed by the patient and not generally offered by the prosthetist. Individuals see this as an additional strain on them and a failing of the prosthetist in their service:

With regard to improving the service I receive, wish they were more able to think outside the box and offer me solutions to problems rather than me having to lead. (Sean, email 257-258)

The difference between a "patient-led" system in which patients are intrinsically involved in the process and a system which places the responsibility for leading the interaction on to the patients are clearly felt by the patients. The way in which the individuals and the prosthetists view the rehabilitation process has the potential to impact on

their experience. The expectations of the individual of this system and how they perceive it forms the final theme within this chapter.

Expectations of the system

Expectations and assumptions regarding the rehabilitation process have the potential to impact upon an individual's experience of limb loss and prosthesis use. Individuals hold a particular set of expectations regarding the process of rehabilitation and the system within which it operates. In cases where the actual service received falls short of these assumptions this can lead to frustration and dissatisfaction.

A regularly raised example of this is a lack of appreciation of the impact on daily life of prosthesis use. This was considered to be problematic in circumstances where the individuals felt they were being impeded by the prosthetists and the system within which they were operating. While appreciating the limitations imposed on the prosthetists within this system, the individuals offer a sense that the impact on their life was not a priority or was not recognised which could cause frustration. This frustration stemmed mostly from what was considered to be an inflexible system which was unable to provide them with the aid they needed in a timely manner and presented them with additional difficulties. In most cases the individuals were careful not to present their experience as a personal attack on the prosthetists, in most cases they were keen to stress that the prosthetists themselves did a good job and they were satisfied with them personally; never-the-less the systematic limitations placed upon them impacted on their daily living and this was difficult to contend with:

I know it's not easy but I feel like it takes ages for me to get anything done (...) Like if I go and get cast then maybe...I dinnae want to down cry the prosthetists or that there cause I know they're only doing their job and that but I suppose it comes down to me feeling like it's my life eh? It's no like the dentist or that, if it takes 2 months to get an appointment then fair

enough but if that takes me 2 months to get an appointment then it might mean I've got a month of not being able to get out of the house. (Sam 315-321)

The underlying problem here appears to be a lack of effective communication between the two parties in order to make each aware of the concerns of the other. The sense of lack of control felt by patients and the blame being placed on a lack of interaction between not only the patient and the prosthetist but other departments was keenly felt:

A lot of time has passed and I've been in this sort of purgatory, the land of no-where. I'm not blaming anyone but there is no holistic overview, that's what I'm getting at. I seemed to have been.....yes, the cardiovascular people, yes they do a great job. You are passed, somebody else does not such a great job - you're passed - you go on, you're passed to someone else. The cardiovascular people are specialists, they are not diabetic specialists. The orthotics people are specialist but they are not diabetic specialists. (Tom 139-144)

Again the individual is keen to avoid placing blame on a particular clinician and emphasises that each department does do a good job; however, his description of his own experience gives a sense of the serious impact on his own life of this process. His expectations that the process would work to benefit him are not being met and instead are controlling his life and preventing him from successful rehabilitation.

The frustration and disappointment they expressed was more often aimed at the NHS as a system, targeting failures in care and blaming a perceived lack of resources for the majority of these concerns. The individuals recognise a limited resource pool within the NHS and reluctantly accept that, while not ideal, this will have implications on the service provision offered:

Yes, I think they are more acutely aware that their budget is so limited, they can't always give what they really, really think would be super for somebody as opposed to being more

than adequate (...) But as I say, everybody is different but there is a lot of people who don't realise that you can get a cosmetic sleeve put on but it's not the sort of thing they advertise because they are really expensive. (Gayle 355-357, 380-382)

With this recognition comes the awareness that these constraints are not always shared with the patient in order to allow a frank discussion of the technical solutions that may be available to them. Further exploration of this point comes with the assertion that often patients are willing to accept a lower level of service as this is what they have come to expect from the system. This relates back to the patient-led debate previously discussed, with only those willing to argue for a better or different approach being offered one:

If i hadn't made a bit of fuss when I've needed to, they would have happily fobbed me off with something substandard. The NHS seems to fail the most vulnerable people. Those who aren't so confident or don't understand how the system works or what they should be entitled to are the ones who lose out & get the worst care. (Sean, email 175-178)

This perception that the NHS may provide a lower quality was expressed in terms of expectations of the device that would be received, the level of service within the department and the institution as a whole. The experiences of individuals suggest a resignation to the limitations of the NHS albeit also a level of frustration. In terms of the device itself, often the perception that the limb would work or look better if they paid to go to a private clinic is expressed:

This is the National Health and I am not belittling the National Health either but you are not exactly going to get the best are you - I remember ((prosthetist's name)) saying that. (Tom 253-254)

This disparity in opinion reflects a lack of understanding of the expectations of the individuals and of appropriate communication within the clinical relationship to address

these issues. Similar opinions are expressed with regards to comparison with military facilities, suggesting that, as with private care, care for military personnel is of a higher standard than NHS and that civilians who lose a limb are not only given substandard care but thought of in a more negative light:

I sometimes feel that they maybe get a bit more preferential treatment (...) and they're brave for doing it and people need to do it and good on them for doing it but I don't think they are any more deserving of a special leg or that than what I am or any treatment, I mean they chose to go to Afghanistan, I never chose to get cancer like you know what I mean? But I do feel they get sorta like "aww well done and the soldiers, we're so proud" but then you never hear anyone saying "aww well done to the boy who had cancer and lost his leg" you know? (...) I'm totally proud of them but I don't think they deserve, I'm no meaning to sound totally selfish or that saying they don't deserve but I think that everyone deserves the same. (Sam 438-446, 460-462)

These perceptions of the impact of the NHS care system on the outcome of their rehabilitation stems from the expectation and preconceived opinions that the individuals hold of the NHS. An improvement in the communication between the prosthetists and the individuals in order to allay these concerns could be beneficial. In addition recognition of the impact of these opinions on the expectations of the individuals would be valuable.

Role of the prosthetist

The role of the prosthetist, as perceived by the individual, is very much one of technical service and provision of the prosthetic device. Individuals expressed the need to have a prosthetist that not only listened to their needs but involved them in the care process. During the initial post-amputation stages, particularly as an in-patient, the presence of a helpful, understanding and proactive care team was identified as being of vital importance in fostering a progressive attitude. Individuals were keen to emphasise the need, not only for

positivity, but also for promoting a dynamic relationship between the individual and healthcare staff. Of greatest importance was that the patient felt able to voice their own opinions and concerns regarding their prosthesis prescription and other aspects of the rehabilitation process. When considering prosthetic support, the provision of this respectful and flexible attitude towards the input of the individual should be considered, alongside emotional support in terms of encouraging positive and enabling adjustment:

I hope that is the case throughout the amputation world. The relationship I have with ((prosthetist's name)) has been first class. He's been adaptable, he's been open to suggestions, you know, he's not had a closed mind, he'll try other stuff and he's always been proactive in prescriptions for higher activity legs. (Tim 500-503)

A “good” prosthetist appears to be one who listens and acts upon requests to provide a device which enables the individual functionally at a level with which they are comfortable. Individuals felt it essential to have a relationship with their prosthetist that allowed them to trust in their professional opinion but at the same time be able to input their own personal experience of using the device:

I think so. I think there's a bit of sort of, he does know much more than me, you know. He thinks a shock absorber will be good. I can't tell that kind of thing but I do know when he was making my new socket and having a text spot inside the socket to sort of protect a soft bit and I'm saying: I think you've missed it there ((name)) I think you've (...) if I had any anxieties I wouldn't worry about it, I wouldn't worry about asking him, you know. I find they do listen. (Holly 670-675)

Openness to discussion and empathetic response to the patients' needs were considered essential, however the individuals in this study appear to look elsewhere for emotional or personal support. This was predominately the case when discussing in-patient care with the nursing staff in particular being singled out for praise and gratitude for their personal

attention and support. Difficulties and dissatisfaction arose when this professional care appeared not to continue beyond the hospital and in a more long-term situation. In particular, one individual who had very little in the way of social support was completely disheartened by the level of support he was receiving in terms of emotional care:

I would appreciate just to feel that someone was caring for me - was actually leading looking after me and that I have never felt since I had the stroke. (Danny 372-374)

His need to be cared for, to have a sense that someone was genuinely interested in his wellbeing beyond that of his medical care was not being satisfied. The difficulty of having multiple care providers over multiple centres and not having one central care worker posed a problem, with a lack of continuity of care. In this case, the individual expressed the feeling that a strong social network was assumed by care staff regardless of the actual home situation. In the absence of this, little professional or structured emotional support is offered and rather depends on the individual health care staff involved in care. The lack of structured, psychological care is apparent with only an ad hoc approach being perceived by the individuals:

They sent me a couple of letters as well just to say "blah, blah, blah if you want anything..." but I can't... I don't think there was anything really. I don't think there was anything specific offered to me. (Sam 1020-1022)

This lack of provision of psychological assistance as perceived by these individuals requires further investigation. A comprehensive appreciation of the current provision of psychological care and the identification of potential benefits of this in rehabilitation, particularly in the absence of a personal social support network, is needed.

From the very early stages in preparing for amputation and the immediate recovery, social support was identified as being of vital importance. This is provided for most from personal relationships and not within a clinical setting. For some, having a wide circle of friends and family to rely on was crucial in the initial stages:

The day I came back from finding out I was getting my leg amputated I spent the whole journey home phoning people and even my mum thought that was brave but I just felt I wanted to tell people. I phoned my brother. I phoned my mates because they all knew what was happening and they were all like: You're joking! (Sam 823-826)

In this case, sharing the burden of the diagnosis with his closest family and friends was essential. His need to share the experience with others gave him reassurance that he had a support network to rely upon. Emotional support from a social network, beyond even that of family and close friends, can be found in many areas from work, leisure pursuits or community groups.

As well as the positive contribution of social support, the potential difficulties that may arise in the absence of such a network were identified. The importance of a strong support network and the feared difficulties of coping and motivating oneself if this system of support were not in place were evident:

I think everybody around me as well , my dad, my brother , my mother, they would never let me sort of ...Because I think it would be easy if I never had a good family or an amazing family, an amazing girlfriend and great friends and that. I think it would be easy if something like this happened to you to just sit in a corner and forget about life all the 'gether (Sam 652-657)

This concern was shared by several individuals who expressed concerns that without their support network they may not have achieved the level of rehabilitation that they felt

was possible. The support and encouragement given by family was not only relied upon by individuals but recognised as an essential element to their rehabilitation.

This lack of support network was alluded to in several interviews where the individual emphasised the need for independence and personal, emotional strength:

I don't have any support, I can't afford to have limitations so there is nobody going to do anything for me, I know that, even in emergencies, for example, how would I get out of here in a fire, I know I could walk down the stairwell, I don't want to do it but I could do it very slowly, one step at a time, holding onto the bannister, using the stick but I could do it.
(Gareth 532-536)

In this extract, the value of support networks is apparent in its absence. The suggestion that support allows an individual to admit weaknesses or limitations, a luxury which this individual felt was unavailable to him. The lack of support network means that he has had to become self-reliant and independent even when this is difficult or poses challenges. Individuals in this group did not consider the prosthetists to be a source of specific social support over and above that of technical provision of the device. Where social support networks are not available or do not provide adequate care, provision does not appear to be being made at a local, clinical level to address such issues beyond that of in-patient healthcare staff.

Chapter summary

Aspects of communication have the potential to be hugely influential on the experience of both prosthetists and individuals following amputation. In the initial stages of pre-amputation preparation and throughout post-amputation adjustment, the information that is conveyed to the patient and their understanding of that information is highlighted as being of importance to the individual. Difficulties may arise when information is not shared or understood in an appropriate manner. The prosthetists in this study were mostly of the

opinion that where possible every opportunity is taken to ensure that patients have a full understanding of the procedure and outcomes. In addition they considered them to be intrinsically involved in the decision-making process. This perception was not equally shared by the individuals who often described a complete lack of understanding of the process to the extent that even the need for an amputation was not fully appreciated. While the procedures of the hospitals as reported by the prosthetists should involve a full discussion with patients regarding all of the potential outcomes and treatment plans, this experience does not necessarily mean that these discussions did not take place, but rather that the patients' lack of understanding was not fully appreciated. The discrepancy between the reports of individuals and prosthetists in these cases suggests a lack of effective communication.

Sharing of information was viewed as a key part of the interaction between patient and prosthetist. However, the amount of information that should be shared is debated. Whether this should always be at a full disclosure level or limited in some way so as to "protect" the patient is dependent on the individual. That this information may be deliberately withheld in order to protect the individual and enable them to focus on the immediate aspects of their rehabilitation could be considered a positive slant on this communication issue. Concerns were also raised about the level of patient involvement in the process. While prosthetists strive for a "patient-led" approach, there are apprehensions from individuals of this leading to disproportionate responsibility being placed on the patient and some individuals being disadvantaged as a result.

Expectations of the system of care at both the local and NHS level were discussed at length, including aspects of dissatisfaction with the system and an awareness of the limitations that are put upon the prosthetists. These range from time from fitting to delivery of the device, flexibility of the system and the provision of a multi-disciplinary care team. The limitations and constraints appear to be mostly related to funding issues, which in turn

lead to provision implications. Negative comparisons were also made between the NHS and private or military care. The prosthetists express difficulties contending with limitations imposed on them by the system in their attempts to provide not only what they consider to be the most appropriate care for their patients but also one which the individual will find satisfactory. Often they must strike a balance between what they can reasonably provide within these constraints and what the patient may be expecting or desiring from their device. Prosthetists' perceptions reflect what they consider to be a lack of understanding of these issues from the patients. Discussion of these constraints and the impact that they may have on service provision and rehabilitation between parties appears to be limited. Patients, while expressing an awareness of limitations on a superficial level, were not always aware of the specific impact it has on the provision of care. In most cases they discuss the systematic limitations in terms of the impact that delays in appointments, the lack of a flexible system or a desire for more expensive technology in terms of the impact on their daily lives. In addition they perceive a distinct lack of appreciation of this impact or a desire to counter the effects from the prosthetists.

Finally, the role of the prosthetist and their relationship with the patient is discussed. The view of this role varies from technician and representative of the healthcare system to counsellor and friend. The prosthetists perceive themselves as having a multitude of roles to play which presents a difficulty for them as a profession as they often struggle to balance each in their clinical assessment. The negotiation of these multiple roles is important for both parties in terms of the way in which they are prioritised in meeting the individual needs of each. This is particularly evident in the need to create an open communication with the patient to enable an empathetic relationship. This may also require the management of non-technical and psychological issues. In contrast, the patients view the prosthetist primarily in terms of their technical expertise and the provision of their device. Additional care and support appears to come from other healthcare professionals, primarily nursing staff, while

in in-patient care. This role is replaced with friends, family and other social groups in the long term. Where social support was lacking or where the prosthetists genuinely felt that an individual was in need of psychological support, such a system is lacking and should be addressed. While the individuals in this study did not see the prosthetists as fulfilling a psychological support role it should be remembered that they represent only a small sample of the population. Each prosthetist's experience is based on their clinical relationships over a long time frame with a wide range of patients. The focus which they give to the lack of psychological support and the level of difficulties which they report in dealing with such cases suggests that this warrants further investigation. Similarly, the individuals in this study volunteered in order to discuss their experiences and, for the most part, were keen to express their high level of adjustment and function following amputation. The level of psychological distress individuals in the current study discussed may not reflect the breadth of the limb loss experience of a wider population.

Chapter 8: Discussion

This thesis offers an insight into the understanding and concerns of those individuals who have experienced limb loss and also offers a novel viewpoint of the prosthetists' understanding of this experience. While the experiences of prosthetists and patients have previously been considered and compared from specific angles, for example prosthetic device prescription or phantom limb experience (Mortimer et al., 2002; Mortimer et al., 2002; Mortimer et al., 2004; Schaffalitzky et al., 2011; Schaffalitzky et al., 2011), this thesis offers an exploration of the overall lived experiences of both groups in order to compare their overall understandings of limb loss, prosthesis use and rehabilitation.

It also presents the opportunity to consider the ways in which comparable or divergent understandings may impact on the rehabilitation process. By comparing and contrasting the views of both parties, this study offers a unique view point on the potential areas of influence that the prosthetists' personal perspective may have on both their own experience and that of their patients. The relationship between these two parties as well as the expectations evident on both sides is of vital importance in the rehabilitation process. The interaction between patient and practitioner is central to the success of this relationship. In order to maximise the effectiveness of this relationship, the shared understanding that each partner has of the other's perspective is essential. In cases where such understandings are divergent, there is potential for dissatisfaction from either party leading to a less effective partnership and rehabilitation. By understanding this relationship more fully and considering the understanding that each has of the others' perspective, we are able highlight potentially problematic areas within clinical practice and suggest developments to benefit both patient and practitioner. The experiences of both groups in this study reveal four key themes in the construction of the understanding of limb loss, prosthesis use and rehabilitation namely Personal Identity, Social Identity, The Prosthesis and Communication.

Personal identity

As seen in chapter 4, the negotiation of new personal identities and the maintenance of pre-amputation identities are key aspects within the experience of limb loss, prosthesis use and rehabilitation. Within the two groups of participants in this study the area with the most shared understanding was that of the importance of “Unique Normality” as the main goal of the rehabilitation process. This necessitates consideration of the specific elements of rehabilitation which were relevant for each individual in order enable them to return to a level of pre-amputation normality. The importance of minimising curtailment of life through the use of a prosthetic device is prioritised by both parties. Prosthetists and individuals have a shared understanding that “normality” is an entirely subjective concept. This cannot be generalised but rather needs an in depth consideration of each individual’s circumstances and priorities in order to integrate these most usefully into the rehabilitation process.

The prosthetists’ experiences reveal particular views on aspects of identity and the impact of individual attitude on rehabilitation outcome. Identity following amputation is defined by the acquired, physical impairment of amputation. Patients’ identities are categorised on the basis of the impact of the amputation with the use of dualistic terms such as “disabled” or “non-disabled”. Through this application of dualistic categories, the prosthetists make judgements on the patients’ reaction to the amputation and also on their willingness to engage with the rehabilitation process. Such categories are considered to be static with prosthetists assuming that these changes to identity are fixed on a long term basis.

While identity categorisation is thought by the prosthetists to impact on successful rehabilitation outcomes, so too is the perceived attitude of the individual on entering the process. A positive attitude and active participation of the individual regarding rehabilitation is thought to ultimately determine a successful rehabilitation and predict adjustment to amputation. The attitude of individuals is not considered simply to be a bonus in terms of aiding the prosthetist in their role but in fact is seen as a key determinant of success.

Individuals who have lost a limb also indicate the unavoidable renegotiation of personal identity. In this case however, this is a more dynamic, fluid and multifaceted process than is perceived by the prosthetists. Post amputation identity is unlikely to be based on one aspect of self such as the categorical terms used by the prosthetists but a dynamic range which varies according to time and context. Individuals are keen to avoid identification based solely on their physical impairment and seek to either integrate this into their self-perception or to minimise its impact through focusing on other aspects of them self. In addition, the terms related to impairment are renegotiated in order to make them more acceptable to the individuals' sense of self perception.

Individuals in this study agree that a positive attitude and active engagement in rehabilitation is essential. This is viewed not as a choice but as a necessity with the alternative option of not engaging and allowing their life to be limited by the amputation being non-viable. In addition, changes to personal attitude and reassessment of life priorities are seen as a positive result of amputation. An over reliance on patients to have the "right attitude" should be avoided but rather seen as a non-essential but useful complement to the skills of the clinicians.

Both groups in this study cite the desire to enable a "unique normality" allowing a return to a level of personally determined, pre-amputation functioning where each individuals' own priorities and personal goals are met through prosthesis use and rehabilitation. Prosthetists report that patients often have what they consider to be unachievable expectations of their device. The prosthetists view resources as a limiting factor in their ability to meet the expectations of the patients, however, they also perceive that patients have unrealistic expectations of the technology available. During the clinical process, patients report a lack of understanding and empathy from the prosthetists with regard to their specific needs and priorities. This suggests the need for greater explicit examination and consideration of these priorities in the rehabilitation process.

The renegotiation of personal identity by individuals post amputation reflects a conceptual readjustment of the terms most often associated with limb loss and disability. This confirms the assertion of Hamill and colleagues (2010) that resistance of such identification involves the renegotiation of the terminology surrounding it. In accepting that the circumstances of limb loss may result in the application of such terms, the terms themselves are reanalysed and adapted in order to fit into the individuals' views of themselves. This allows the individual to maintain an acceptable personal identity which is separate from their own previous views of such terminology for example, making a qualitative distinction between disabled and handicapped which assumes cognitive impairment. This renegotiation of perceptions of disability and the use of technology to negate the limitations imposed by amputation supports the findings of previous studies (Hamill et al., 2010; Saradjian et al., 2008). Rejection of such terms does not necessarily relate to lack of adjustment as suggested by the prosthetists in this study, rather a renegotiation of personal meaning.

The range of opinions and experiences shared in this study reflect the variety of ways in which other individuals who may be similarly socially categorised make sense of the use of disabled versus non-disabled terminology as discussed in the psychological literature. It has been suggested that the term "disability identity" consists of an affiliation and solidarity with others who experience disability (Putnam, 2005). However, debate continues over the conceptualisation of this personal identity and whether the presence or absence of such an identity is necessarily a positive or negative concern. Olkin (1999) suggests that there are three distinct groups within disabled identity. Firstly those who have some functional limitation and identify them self as a person with a disability but who often can "pass" as non-disabled due to the level of their limitations or the use of assistive technology. This group may or may not self-identify as disabled. Secondly those whose disability is an integral part of their self-concept, either in a positive, negative or ambivalent way. Finally,

those for whom disability is a social construct and civil rights issue who often identify as disability rights activists. These varying levels of identification with a disabled community are reflective of the post amputation experiences of individuals in this study. Olkin (1999) highlights the importance of recognising that there will be people who, while having what may be considered impairment, do not identify as disabled and do not experience the level of affiliation suggested by Putnam (2005). Such experiences were evident in this study particularly by individuals who did not wish for their pre-amputation identity to be superseded by the acquisition of a physical difference but who rather based their identity on non-physical attributes. In these cases, identification with disability was only particularly relevant when the amputation and subsequent physical concerns became obstructive to achieving their life goals and was therefore brought to the forefront of their attention.

The importance of the ability to set and achieve personally relevant life goals during adjustment to amputation has been previously highlighted in amputation rehabilitation literature (Coffey et al., 2009; Hamill et al., 2010). In particular, the relevance of such goal adaptation and adjustment for self-reported social adjustment, independence and well-being found in previous studies is similar to the experience of individuals in this study. Identity is reported in disability literature as being created through the combination of experiences, social roles, abilities and goals that the individual values (Dunn & Burcaw, 2013). The acquired disability becomes merely one of these aspects which may be activated depending on the circumstances. An individual may choose to align themselves or resist such identification in different contexts. An understanding of this multifaceted and dynamic construct of identity and the particular meaning that such terminology carries for the individuals appears to be lacking with the prosthetists in this study. The application of categorical identifiers by the prosthetists raises concerns both of their understanding of the patients' experience but also of the potential judgments of the individuals that they may make based on these. With regards to the potential for differential treatment of patients with

disabilities, Olkin (1999) warns that “as clinicians, we are subject to all the same factors that influence others, and are not immune to prejudice” (1999, p.74). Similarly it has been reported that the attitudes of health professionals to individuals with disabilities have the potential to negatively influence rehabilitation (Paris, 1993). As such, the implications of any categorisation of patients and possible judgements thereof should be carefully considered.

The level of prominence assigned to physical impairment in the creation of self-identity in this study is reflective of discussions by Watson (2002). The current study supports findings that the construction of self-identity does not necessarily include that of “disabled” merely due to the presence of a physical impairment; the presence of impairment may contribute to an individual’s identity but does not necessarily become the focus of it. The reluctance of an individual to accept categorisation by virtue of their impairment and their reasons for doing so are important in understanding the experience of physical impairment. This is particularly relevant with an acquired impairment such as amputation, and has a potential for impact on rehabilitation. Watson (2002) additionally highlights the dynamic and fluid nature of the impact of disability on personal identity and the way in which this is influenced by context and experience. This, again, is prominent in the experiences of individuals in this study who considered the influence of their impairment on their identity to differ according to circumstances. This is in contrast with the static and dualistic view held by many of the prosthetists and highlights the need for a fuller understanding of the importance of personal identity following limb loss.

Prosthetists and individuals diverge in their understanding of the role of personal identity following amputation; similarly discrepant perspectives are evident with regards the influence of personal attitude and reaction of the individual to the amputation. Once again, the meaning that is ascribed to this opinion in terms of the overall experience differs. For those who have lost a limb, the sense that a positive attitude and active participation in

rehabilitation is essential. However this is tied to the perception that there is little option to the contrary, and does not necessarily relate to emotional acceptance, merely a practical resignation. This finding is similar to previous studies which highlight participants' acceptance as being associated with having little or no choice (Hamill et al., 2010; Saradjian et al., 2008). The experiences of the prosthetists' reflect the opinion that not only is this positive, active attitude desirable but that it has the potential to augment or diminish clinical rehabilitation. This puts a high level of pressure on individual's to react in an appropriate and positive way while deflecting responsibility from the prosthetists' professional input. Developing a positive attitude following amputation and playing an active role in the process were viewed by individuals as being ways of taking control of the situation and maintaining personal ownership of this aspect of their lives which is reflective of previous research (Liu et al., 2010; Saradjian et al., 2008). While this is something that could be integrated into the clinical rehabilitation process, the level of rehabilitative success that can be attributed solely to this one aspect may be overplayed by prosthetists in this study, reducing their level of professional responsibility on the process.

Social identity

Chapter 5 highlighted the role of social identity within the experience of limb loss. This was defined as how individuals see themselves within a social setting and the way in which others may react to them. Both groups identified social aspects of identity and the role which the prosthesis plays in facilitating this as being central to the experience of limb loss and rehabilitation. The perception that appearing "different" to others would lead to negative judgements was pervasive in both groups. While for the most part this was associated with prioritising "hiding" the amputation and the device, for some individuals this was not a concern and the device was actively displayed. The greatest priority for both groups was the provision of a device which enabled a favourable, functional comparison with others. Similarly, the continued fulfilment of social roles which were integral to an

individual's social identity was a key function of the prosthetic device and a central part of the rehabilitation process.

Prosthetists considered the presentation of a “whole” self to be central to social integration for individuals who had lost a limb and, as such, prioritised this within their clinical role. This essentially entailed allowing the individual to appear as though they had not lost a limb. This was not in terms of providing a cosmetically perfect replacement for the amputated limb but one which allowed functional integration and the ability to conceal the amputation in a social setting. While this was often the priority for individuals, a significant subset also declared little interest in “hiding” the amputation as long as functional ability was maintained. Social Identity was dictated by function and not physical appearance.

Social support was considered by the prosthetists to be a “make or break” factor in rehabilitation and adjustment to amputation. Individuals who lacked strong social support were perceived to fare much worse than those who had a support network to rely on for moral and practical support. Despite this assertion however, concerns were evident of the level of “appropriate” support that was available. Such support was thought to include encouragement but without leading to reliance. Similarly concerns were presented around support which raised individuals' expectations of the rehabilitation process and prosthetic device. This was thought to introduce an additional dimension for the prosthetists to “manage” which was considered to be problematic from their point of view.

The prosthetists viewed social comparison as an additional essential element to the rehabilitation process but raised similar concerns as to that of social support. The ability of individuals to compare themselves to other people who have lost a limb was recognised as vital. However such comparisons were thought of, again, as having the potential to raise the expectations of individuals of the clinical process and in turn of the prosthetists. Again this

was considered to be potentially problematic for the prosthetists in their clinical role rather than focusing on the meaning it held for the patients. The importance of such charities as the Murray Foundation and other support groups to fulfil this need was recognised and appreciated as it was thought to remove this responsibility from the prosthetist .

For individuals, social support was considered to be an essential factor for rehabilitation and adjustment as they adjusted to limb loss. Those who reported having what they considered to be a strong support network cited this as being one of the key elements of their successful rehabilitation and adjustment. Those without a social network on which to rely similarly blamed this lack of support for their apparent dissatisfaction in their progress. Social support from family and friends was rated as being essential for motivation including encouragement for high levels of achievement in rehabilitation and prosthesis use. Such encouragement is similar to that which the prosthetists identified as being potentially detrimental due to the unattainable expectations it may promote. However, such detrimental effects were not identified by the individuals in this study, who focused only on the positive inspiration and meaning it afforded them.

Finally comparison to other individuals who had lost a limb was essential in negotiating social identity and rehabilitation, on a variety of levels. Firstly social comparison for motivation and encouragement was actively sought. An attitude of “if he can do it then so can I” as a result of this comparison was evident. This came with some limitations however as the direct comparability of the other individual needed to be high in order to provide the greatest motivation. In ideal circumstances the object of comparison should be recognised as being of a high level of likeness to themselves in terms of life circumstances. The ability to recognise themselves in terms of priorities and potential achievements was important in maximising the benefit to be gained.

The priorities both within and between prosthesis users and prosthetists in this study were divided between a desire to hide physical difference within a social setting and displaying it. This expression of differing reactions to public prosthesis use has been previously found suggesting this is a common theme within the experiences of people with amputation (Hamill et al., 2010; Murray, 2005; Murray, 2009; Saradjian et al., 2008). Concerns regarding the perceptions of others centred on a desire to avoid appearing, or being treated, differently. While this perception was in some cases the result of actual instances of altered treatment, in other cases the assumption that differing treatment would be forthcoming was enough to impact on their behaviour and experience. This had previously been suggested in the findings of Rybarczyk and colleagues (Rybarczyk et al., 1995; Rybarczyk, Nicholas, & Nyenhuis, 1997) who suggested that perceived social stigma was an important factor in adjustment to amputation and had the potential for negative influence on psychosocial adjustment post amputation. The perceived or actual reaction from others with regard to their amputation appears to influence the meaning that individuals attach to this and their subsequent actions. Individuals perceiving a negative social reaction (or one that is different to that which they would have experienced prior to limb loss) wish to protect their pre amputation identity and the social acceptance that goes with it. Of key relevance here is the ability to function as per pre-amputation, in terms of being able to walk without obvious difference, to continue to work and to socialise and to play an active role in family life. While aesthetically, anatomically realistic devices have been shown to be particularly relevant to the social meanings of prosthesis use for upper limb device users (Murray, 2009; Saradjian et al., 2008), for lower limb device users in this study, their social identity was far more related to the ability to function effectively rather than cosmetic, prosthetic concerns. This was due to the function that a lower limb provides such as being able to walk without limping, standing for extended periods without drawing attention to oneself rather than the more socially intrinsic aspects of upper limbs such as shaking hands and gesticulating while talking where the missing hand or upper limb would be more obvious.

The presentation of self as a non-amputated individual with intact functional abilities was at the forefront of clinical aims for the prosthetists. Many of the prosthetists' assumptions of patients' priorities were influenced by their own perceptions of what they personally would wish in that situation. The preservation of social roles and the enabling nature of the prosthetic device to this end was clearly apparent in the prosthetists' priorities. However, this was often based on the assumptions of the prosthetist and their interpretation of the needs of the patient rather than the explicit discussion of such issues with the individual. Several studies have suggested the need for fuller integration of the patients' needs into the prescription process and patient involvement in the rehabilitation process as a whole (Nielsen, 1991; Schaffalitzky et al., 2011). The lack of literature investigating the prosthetists' specific understanding of these aspects of amputation and prosthetic experience means that this finding warrants even further investigation. The prosthetists' attempts to understand the patients' perspective are admirable; however the lack of explicit attention to the needs of the patient and the use of assumptions based their own perceptions should be met with concern. These divergent understandings have the potential to influence the individuals rehabilitation in terms of the way in which they integrate into society post-amputation, their social support network, and occupational or leisure pursuits. Such aspects should be considered from a clinical point of view in order to fully integrate individual priorities, concerns and anxieties in clinical decisions.

Both parties identify levels of social interaction and support as significant to the post amputation experience. The importance of social support networks to post amputation adjustment has been emphasised through patient research in previous years (Hanley et al., 2004; Rybarczyk et al., 2004; Williamson, 1998). However, in relation to the perceived appropriateness of support provided, individuals and prosthetists highlight cases whereby the family and individual themselves may be promoting a view of rehabilitation which the prosthetist considers to be inappropriate or unachievable. Previous studies have suggested

the provision of unhelpful or maladaptive support from family (Gallagher & MacLachlan, 2001; Hamill et al., 2010). In the current study however, prosthetists' concern regarding this appears to centre on the influence that such support may have on the patients' expectations of the service which should be provided rather than a concern for impact on the patient themselves. Such expectations may be discordant with the service that clinicians feel they are able to provide creating difficulties for them in their professional role. The meaning of support for individuals should be considered by clinicians and in particular the varying nature of such support. In these circumstances, prosthetists perhaps need to accept that a by-product of patient support may be the use of clinically misguided statements. The role of the prosthetist in such circumstances may be to take a hand in addressing such influences through improved interaction and communication with the patient and their families where needed.

While the prosthetists have a professional interest particularly in the functional aspects of the device which they provide and the role that this plays in the comparison with others in a social sphere, other aspects are raised as important by those people who have lost a limb. Heightened vulnerability, the revelation of highly personal and intimate concerns to strangers as well as loved ones and the particular impact of amputation on social and familial roles are highlighted as important in the post amputation experience of these individuals. Each of these aspects have been raised as concerns in previous studies with varying degrees of importance (Hamill et al., 2010; Murray, 2005; Murray, 2009; Saradjian et al., 2008; Senra et al., 2012). Current results show that social comparison particularly from a coping mechanism perspective for individuals in early stages of rehabilitation was an essential factor. Comparison with other individuals of a similar clinical condition was considered essential to rehabilitation both in terms of physical motivation but also psychological relief from anxiety. Such comparison was rated more highly than many other attempts at reassurance including those from friends, family or prosthetic staff.

While the prosthetists recognised the benefit of comparison to other patients, an understanding of the level of importance that this comparison holds for the individual appears to be lacking. This is particularly with regards to the specific aspects of comparability that are available. From the patients' perspective it was not necessarily enough to have the opportunity to compare oneself with just any other patient. The personally relevant features of the comparison were essential. The prosthetists relayed fears regarding the appropriateness of the content of the support that would be offered by such a comparison. While these fears are presented as being in the best interest of the patient so as to ensure the greatest benefit gleaned from the experience, the basis of these fears appeared to be more centred on the potential to influence the expectations of the patient. While the importance of social comparison is recognised, the specific reasons for its benefits and the most helpful way of providing this support in order to benefit the patient most fully should be considered. Again, the influence of these concerns on the priorities of individuals in the rehabilitation process should be recognised and integrated at a clinical level in order to ensure that the areas of particular importance to each individual is catered for.

The prosthesis

Chapter 6 revealed a variety of shared experiences regarding the role of the prosthetic device in terms of impact on life, expected outcomes of rehabilitation and the clinical process. An important aspect of this theme involves the variety of expectations that individuals have of their device and of the clinical system in which they now find themselves. These varied views may be due to the interaction of a variety of issues such as health issues, personal and social circumstances, previous levels of activity or differing levels of priority. In addition, outside sources such as media attention, comparison to other individuals or the opinions of other people has the potential to influence these expectations (Hamill et al., 2010; Murray, 2005; Murray, 2009; Saradjian et al., 2008).

In this study, prosthetists perceive that their patients have an expectation that the prosthetic device will provide them with a quick, easy solution which will restore the function of their amputated limb. Influence on these expectations ranges from the media portrayal of non-representative, high profile amputation to comments from family and friends. Patient expectations of their prosthetic device are often raised to levels which prosthetists consider to be unobtainable in many cases. This unbalanced comparison of the patients is perceived by the prosthetists as consisting of an understanding of “We both have below knee, lower limb amputation therefore I should be able to achieve that too” without recognition of such issues as age, fitness levels, comorbidities and the importance of such factors in rehabilitation and prosthesis use. As a result of these influences, prosthetists identify their role as managing patients’ expectations to ensure that their view of the device and the achievements that they are likely to attain are more in keeping with that which the prosthetists are confidently able to provide.

In terms of living with the prosthesis, the goal of the prosthetist is cited as enabling the patients to return to “normality” in their daily life. The device itself is perceived to be central to rehabilitation and achieving a high level of life satisfaction and social integration. Despite this goal of personal empowerment for the patient, prosthetists have their own expectations with regards to what the goals and outcomes of the individual patient should be. Again this is thought to necessitate the management of the expectations of the patients which may be misguided as far as the prosthetists are concerned. As clinicians, the prosthetists’ goal is enabling physical rehabilitation and function. This goal dictates their priority in many cases particularly when asked to choose between various aspects such as function versus cosmesis. While it may be necessary for the prosthetists to tailor the individuals’ expectations if they are deemed to be unachievable given the individuals’ circumstances, this should be done with the explicit involvement of the patient in their decision making process.

In line with the prosthetists' view, many individuals do admit to thinking that the prosthesis would "replace" the amputated limb, particularly in the early stages of rehabilitation. The expectations of the individuals were very much influenced by portrayals of high profile prosthesis users as similarly identified by the prosthetists. Through this comparison grew the assumption that their own experience would be reflective of these other individuals. In cases where the device did not enable such achievement, or an alternative reality was realised, then a renegotiation of life priorities and meaning was required. Often this was difficult to contend with and a source of blame was sought, such as the device itself or the limitations imposed by the system. The device was seen as the source of rehabilitative success, often with little regard or appreciation for the physical and practical limitations imposed by prosthesis use or the importance of other personal factors such as fitness levels and comorbidities. Such seemingly over-ambitious expectations often create a source of interactional conflict as the individuals perceive the device and the prosthetist as impeding their projected rehabilitative success.

The device itself was seen as both enabling and limiting to differing degrees in different contexts. While the device was functioning well and meeting the patients' needs it was considered to be invaluable. When the device failed however this led to a realisation of the level of dependence that was present and frustration at the limitations that this imposed on their life. Such control was evident at higher levels such as dependent living and spontaneity but also on a more daily basis such as clothing choice. This created a dual meaning of the device between positive enabling and negative control which the individuals had to balance in their understanding. Ineffective or inappropriately prescribed prostheses were seen as restricting rehabilitation and limiting independence, imposing unwanted levels of control on the individual. This was described by an individual in one study as "My wings are clipped" (Norlyk, Martinsen, & Kjaer-Petersen, 2013) similarly to one individual in the current study who described himself as "a fly, caught in a spider's web, getting nowhere, struggling,

struggling” (Tom 316-317). Such difficulties caused by inappropriate prescription or limitations imposed by the system underline the need for effective communication in this relationship to ensure that the best possible care is provided by the prosthetists and similarly perceived by the patients.

The priorities for the individuals centred on their personal needs from the device. In the majority of cases this involved an initial ranking of function and comfort over any other aspect. If function and comfort were satisfactory this led to changes in self-perception, confidence and added a new level of meaning to the use of the device. Conversely, problems with these aspects were seen to influence the overall experience of prosthesis use and have a negative impact on both daily life and the individuals’ self-assessment. The device was first and foremost considered to be there to enable function but with this comes personal satisfaction, confidence and ability to live in whichever way the individual identified as important. The way in which the device features in the individuals’ assessment of their life world was central to their experience. This could be further developed through research and clinical practice.

Difficulties encountered in using the device and in particular the physical effort required came as a surprise to most individuals and led to high levels of upset and frustration. A lack of preparation and information with regards to the process of rehabilitation and learning to use a prosthetic device is highlighted as being problematic and the root of many of the difficulties encountered in this initial stage of recovery. Similar experiences of the differences between expectation and experience are expressed in previous studies (Schaffalitzky et al., 2011; Sjö Dahl et al., 2004; Van Der Linde et al., 2007) with concerns being raised regarding the prosthetists’ understanding of the patients’ priorities. Often individuals do have to come to terms with the difficulties they are likely to face in prosthesis use and this is a necessary part of the interaction between patients and practitioners. It may be that patients require improved information and consultations regarding this which will

necessarily fall to the prosthetists in many cases. However, it is important to ensure that any such preparation specifically challenge the aspects which individuals find to be most troubling rather than attempting to match the patients' expectations to the predetermined priorities of the prosthetists.

The specific influences of media sources on the patients' expectations of the prosthetic device are a key finding of this study. While previously such influence has only been briefly mentioned (Hamill et al., 2010), the findings of the current study highlight its potential for great impact on the experience of individuals following limb loss. Media portrayals of highly functioning individuals successfully using a prosthetic device are seen by prosthetists as setting the tone for the expectations which patients present at rehabilitation clinics. Their focus on the difficulties caused by such differences in experience and expectation revolve more around the impact it has on them as professionals rather than focusing on how to integrate these differing perspectives more fully into the rehabilitation process. This is also reflective of the differing perspectives of both the patients and the prosthetists as have been found previously (Pezzin et al., 2004; Schaffalitzky et al., 2011). Recognition of the variety of expectations which individuals may hold, the influences which may have contributed to these expectations and the impact that they may have on the rehabilitation process should be more fully considered and assimilated into the clinical process in order to reduce the discrepancy between expectation and experience.

In this study, both groups expressed their desire to use the device as a mechanism to enable individuals to achieve a level of functionality in their lives to return to what they considered to be a level of pre-amputation "normality". This was recognised by both parties as being very much a personally defined state with each individual having differing priorities to achieve this goal. If a prosthetic device can enable satisfactory levels of activity it can also enable the continuance of a variety of social roles such as occupational, familial or leisure based. Activity restrictions, restriction in daily life and disruption to goals have been

shown to be detrimental to the psychosocial adjustment of individuals following amputation (Asano et al., 2008; Wetterhahn et al., 2002; Williamson et al., 1994). In relation to this, the recognition that the device was responsible for much of their ability to live their lives in the way that they chose was of central importance to their experience. This was relevant to a range of life experiences such as returning to work but also smaller aspects of personal independence such as being able to shop for oneself and reducing reliance on others. Facilitation of such adjustment and maintenance of personally relevant activity through prosthesis use needs to be recognised and facilitated in the clinical process.

While the device was for the most part a successful tool in enabling them in the pursuit of their target individuals also shared frustration at the control that it could impose. These levels of frustration were felt to be exacerbated by a lack of full preparation for the level of interference to everyday life that they could expect. This lack of preparation has been previously highlighted suggesting that there is a distinct lack of effective communication of such information between patient and practitioner (Hamill et al., 2010; Murray, 2013). Some individuals voiced dissatisfaction with the rehabilitation service; this centred around a lack of recognition of the individuals' reliance on the prosthesis and associated disruption when technical difficulties were encountered as well as the lack of a flexible and person centred system. Such frustration often results in personal blame being placed on the prosthetist. Aspects of patient-practitioner interaction were also considered by Murray (2013) expressing dissatisfaction from patients with the systematic limitations imposed on them and the impact that this has on their daily lives. Prosthetists, in the current study, felt that the patients showed a distinct lack of appreciation of the complexity of the system within which they were working while also expressing a focus on the physical aspects of rehabilitation. The lack of joint understanding and appreciation for the point of view of the opposite party shows a further complexity in communication which could go some way to allaying these joint frustrations. A barrier to optimal rehabilitation is discrepant expectations. One possible

recommendation for clinical practice could be to provide literature on patient narratives of coming to terms with their expectations of the device from these more day to day perspectives.

Communication

Complexities in communication were highlighted in each of the thematic chapters in this study. Chapter 7, Communication, specifically identified the need for, and often the lack of, coherent and mutually beneficial communication within the patient practitioner relationship. Often ineffective communication is the central factor in the divergent aspects of other areas of this experience as described in the previous chapters. Murray (2013) suggests the need for attention to be paid to communication between these parties through his study of patient practitioner interactions from the patients' perspective. While Murray's study successfully highlighted aspects of importance within this relationship from the patient perspective, the current study adds to this understanding by providing the view point of the prosthetist to enable comparison and contrast.

From the findings in this study it is clear that there is a level of complexity inherent in various aspects of communication between prosthetist and individual following amputation. These aspects have the potential to greatly influence both the overall experience of limb loss and prosthesis use as well as impact on rehabilitative outcomes. The purpose of communication for the most part was to ensure the effective sharing and understanding of information as well as ensuring a mutually satisfactory assessment of the rehabilitation process. In order to facilitate these outcomes, "effective" communication was cited as being required. The understanding of what such "effective" communication consists of and how it should be applied and measured is where the experiences of these two groups diverge.

Prosthetists approached the concept of patient-practitioner interactions with a focus on sharing information and ensuring a complete understanding of this information on the part of

the patient. In addition, the perception that patients were fully and actively involved in all decisions was evident. Clinical interactions were considered to be patient-led wherever possible, with the prosthetists perceiving themselves to be encouraging patient involvement and striving to meet patient identified goals. However, in many cases decisions were made based not on an explicit direction from the patient but on clinical knowledge and an assumption of what the prosthetist judged to be “best” for the patient.

Often a discrepancy between what the patient and the prosthetist were expecting from the process was perceived. In order to address this misalignment, prosthetists identify the need to “manage” the expectations of the patients. This involved bringing the patients’ expectations in to line with that which the prosthetists can be sure of providing thus minimising discrepancy related dissatisfaction. Communication in these cases involved persuasion, presenting evidence to support the prosthetists case and using a cautious but firm approach to ensure that the prosthetists’ view is adopted by the patient.

The prosthetists interpreted their own role as complex and multifaceted and highlighted issues of balancing the roles of technical specialist to friend and counsellor. The negotiation of these multiple roles often caused difficulty as they strove to balance meeting what they perceived to be the patients’ needs at a variety of levels. A good, successful relationship with the patient was defined as one which enabled a friendly, informal, encouraging environment for patients to feel able to trust the professional. While this was presented as a way of involving patients in the care process, it also served to create an atmosphere in which prosthetists would be able to “do their job”. Encouraging this role to this end is not necessarily to enable higher levels of patient involvement but conversely to reduce it and allow the prosthetists autonomy over the care process.

The role of the prosthetist within the patient-prosthetist relationship was considered to be essential by individuals following amputation. The prosthetist was essentially viewed as a

technical specialist whose role was to provide the device and to be able to make this to the patients' specifications. The individuals felt an ownership of the prosthesis and therefore felt that they should be able to dictate what they needed it to be able to do. A supportive prosthetist was viewed as a positive addition but this was from the perspective of enabling the patients in their identified needs rather than in a psychologically supportive role. This role was provided by in-patient staff and later transferred to the wider social network on discharge. However, if this social network was missing then provision for such support was identified as lacking in a professional capacity.

A key feature of the individuals' perception of the communication process was a reported lack of information. Even when the need for amputation is agreed by the patient, often this was met with a sense of resignation rather than choice. However this did not necessarily mean that the patient accepted or understood the reasoning particularly in emotional terms or with regard to the difficulties they could expect as a result. In terms of the care they received, the individuals' perception of "patient led" care was often equated with "if you don't ask, you don't get". This was judged as placing additional, often unwanted pressure on the individual to be proactive in their care. This was judged as being potentially disadvantageous to some less well-prepared patients. In extreme cases this was viewed as leading to confrontation with the prosthetists rather than the inclusive and cooperative partnership.

Individuals with amputation expressed the perception that private and military care offer a better level of service than the NHS and that limited resources were responsible for limiting the technological specifications of the devices prescribed. A further aspect of communication identified as key was the perceived lack of a holistic experience. Patients identified the need to feel fully cared for in a continuous manner rather than each specialty dealing with only "parts" of the patient as dictated by their particular profession. Such

impressions of disparity were compounded by a lack of communication or information to the contrary.

Communication within the patient practitioner relationship is the gateway to providing effective care for an individual. Just as appropriate care and support has the ability to improve rehabilitation and independence following amputation, so too does inappropriate care have the ability to have a negative impact. The provision of the “right” kind of support and the use of “effective” communication first requires an understanding of what each of these concepts constitutes in this setting. Effective communication first and foremost is needed to share information and ensure a common understanding (Hamill et al., 2010). The prosthetists in the current study considered the patients to play a fully informed, integral role in decision making and to have a full understanding of the relevant information. Individuals reported experience to the contrary often individuals explicitly stating a complete lack of understanding of what was happening and of their alternative options. This is reflective of patients’ experiences of both amputation and other healthcare areas whereby patients raise concerns about a lack of information or true understanding of their circumstances (Mortimer et al., 2004; Ononeze et al., 2006; Pun et al., 2009; Sjö Dahl et al., 2004). Involvement in the decision making process appears to play a large part in a satisfactory experience for individuals. In some case where an elective amputation is planned, a cost benefit analysis can be conducted by the individual. In order to aid their decision process, appropriate information is essential. This level of either actual or perceived control is reported as being important to the patients’ satisfaction with the process (Hamill et al., 2010). Even in instances whereby the amputation is being carried out for life-saving reasons, patients still wish to be given information in order that they feel involved in the process. This is an important point to be considered in the clinical process. While such information may seem irrelevant as the operation is essential in its life-saving capacity, the meaning that it holds for the individual should be considered.

Difficulties arise where patients are either not given appropriate information or do not understand what they have been told. Reports of either inappropriate or a complete lack of information appear to be common in this study and in others (Liu et al., 2010; Mortimer et al., 2002; Murray, 2013; Sjö Dahl et al., 2004). In some cases, while information was given, for a number of reasons it was not understood. Liu and colleagues (2010) describe the differing focus of patients and healthcare staff prior to amputation. While staff are concerned with a focus on the provision of immediately relevant information, the patients were preoccupied with coping with fear and anxiety, questions regarding their future and the practicalities of what would happen next. This is reflective of the individuals in this study who reported that such distracting factors made it difficult for them to give appropriate attention to the information that was given. Similarly rational consideration of such information was impeded by additional circumstances such as pain or dealing with additional diagnoses (Hamill et al., 2010). General difficulties in understanding the information and related consequences have been reported (Gallagher & MacLachlan, 2001; Sjö Dahl et al., 2004; Sjö Dahl et al., 2004). This may be due to the complexity of the language being used or the way in which it was presented.

All such issues should be considered in thinking about the effectiveness of communication. In this study the discrepant views of the individuals and prosthetists regarding the sharing and understanding of information suggest the need for a review of the way in which information is presented. Similarly, regarding the involvement of the individuals in the decision making process. Liu (2010) comments that while individuals may have an intellectual understanding of the need for an amputation; this does not necessarily reflect an emotional acceptance. Similarly an additional study comments on resignation rather than decision regarding the need to amputate from individuals as well as concerns regarding the psychological implications of such a decision (Sjö Dahl et al., 2004). Both parties in this study were motivated to achieve a partnership and a successful rehabilitation

outcome however there are complexities in the understanding of both sides which need to be considered. Such complexities are inherent in examples such as the often misperceived expectations of patients regarding the physical difficulties they will encounter in prosthesis use. Similarly, the lack of appreciation from the prosthetists with regard to the importance of a perception of decision-making to the individuals even when the choices open to them are non-existent may give rise to difficulties.

Further discrepancies in understanding between individuals and prosthetists in this study related to the difficulties patients had negotiating the differences in their expectations of their device and the reality with which they were faced. Often this was the result of comparison with high profile media representations of amputation which caused difficulties for both parties. While prosthetists discussed “managing” these expectations post amputation, a more appropriate scenario may be to prepare the patients more fully and facilitate rehabilitation in a more positive way. The presentation of relevant information regarding the issues which are most central to the patients’ concerns prior to amputation would be beneficial as has been shown in previous studies. Focusing on such issues as the rehabilitation programme, the prosthetic device and possible outcomes have been found to be beneficial (Liu et al., 2010). It has been reported that rehabilitation is more successful when individuals accept the impact of their disability and engage in the process of adapting to the multifaceted changes that impairment to physical function may entail (Saradjian et al., 2008). While this may be the case, it is similarly important for practitioners to understand the personal impact and meaning of such changes for the individual (Schaffalitzky et al., 2011). In this way, the facilitation of acceptance of impairment can be effectively included in the rehabilitation process.

Differences in expectations and priorities with regards to service provision and prosthesis use are evident in the current study. Such discrepancies have been reported to varying degrees in past studies (Liu et al., 2010; Murray, 2013; Norlyk et al., 2013;

Schaffalitzky et al., 2011). Prosthetists tend to concentrate on the practical, physical aspects of care with a particular focus on mobility. Patients on the other hand focus on life impact and personal concerns such as independence and future options. This difference in focus can lead to a lack of appreciation from the prosthetists as to the issues of concern for the patients which can translate as dissatisfaction with the service provided. Similarly such focus from the prosthetists can be interpreted by the patients as a lack of attention to their specific needs. Such discrepancy in focus is apparent in this study. In the current study, disparity between what the patients expected to receive and the service which was forthcoming led to frustration for both parties. Often this was interpreted as a lack of willingness from the prosthetist to provide the care that the individual sought, or as a lack of appreciation from the individual of the complexity of the system within which the prosthetist was working. Similar descriptions of adversarial relationships due to mismatched expectations and experience have been given from the patients' perspective (Murray, 2013). This indicates again the need for improved communication and opportunity for increased awareness of such issues as differences in priority and expectation.

Suggestions for practice

The experiences shared in this study and the limited literature available suggests the need for a potential review of clinical practice particularly with regard to patient involvement in care and patient-practitioner relationships. Whilst patients and prosthetists exhibit shared understanding in some areas; in other areas there is scope for increased joint understanding. The loss of a limb and subsequent use of a prosthetic device has an unmistakable impact on the individual in terms of their personal and social identity which are both intricately related to the use of the prosthetic device and the meaning that the individual attaches to this. While the prosthetists are professionals with an understandable focus on the technical aspects of the prosthetic device, the way in which this device integrates into the individual's life must be included in the rehabilitation process. In order to do this effectively, a more nuanced

understanding of the patients' needs, experiences and priorities must be gained through effective communication and patient involvement.

A clinical practice which effectively combines the physical, psychological and social aspects of limb loss is required in order to understand the challenges and consequences of this experience on individuals and to meet their rehabilitative needs. Norlyk and colleagues (2013) suggest the need to take this further to considering, not just holistic care on a practical level, but through the implementation of "Life-World led care". This involved considering well-being on an existential level i.e. what does this mean to the individual in such terms as freedom and vulnerability (Dahlberg, Todres, & Galvin, 2009). While this may be difficult to implement at a service wide level, certainly the introduction of consideration of the personal meaning of amputation raised by individuals in this study would be beneficial. Such concerns should be addressed both in the training of prosthetists and in clinical practice. Vocational skills training would also be a beneficial addition in order to facilitate more effective communication. Prosthetists discussed the need to manage the expectations of the patients while at the same time balancing an awareness of the patients' individual needs. However they also expressed difficulties in being able to facilitate this balance. This could be effectively addressed with the introduction of such communication training either at an undergraduate level or through continued professional development. Similarly, several prosthetists explicitly admitted to inadequacies in their training to coping with psychological issues in clinical care despite the regularity with which they were encountered. Again this suggests the need for additional training for the prosthetists, however, an assessment of the need for a psychologist as a member of the clinical team is also implicated.

Considering the suggestion that preparation for changes to life which should be expected with an acquired disability (Saradjian et al., 2008), the inclusion of such information in the rehabilitation process is essential. Similarly, the inclusion of patients in the decision making process is thought to require the provision of relevant and easy to understand information

(Hamill et al., 2010; Liu et al., 2010). Both prosthetists and patients in both this and additional studies suggest the need for comparison with other individuals who have lost a limb in order to provide the individual with a sufficiently comparable example (Murray, 2013; Saradjian et al., 2008). As was identified in the current study, while it may be an ideal situation for each individual to have the opportunity to talk to another prosthesis user prior to amputation, this may not be practically achievable. Rather, it may be a useful exercise to consider the inclusion of comparable narratives from other individuals in the pre-amputation preparation process. These could be presented either in leaflet or video form. Narratives are increasingly being used to engage and inform in health domains. These have been found to be perceived as more relevant to patients than the traditional didactic facts and figures usually presented in patient information leaflets (De Wit, Das, & Vet, 2008; McQueen, Kreuter, Kalesan, & Alcaraz, 2011). While such methods are not commonly used in amputation rehabilitation and prosthesis use, they may offer a method for increasing the provision of relevant information and empowering patients in decision making. In a similar vein, preparation for the reality of prosthesis use is also apparent. On several occasions individuals alluded to the inappropriateness of the clinical setting for preparation for using the device in the “real world”. Suggestions for the addition of “realistic” terrain such as stairs, gravel, slabs or grass on which to practice would give a wider benefit to patients as they take the step from clinical use of the device to everyday wear.

The role of both the patient and the practitioner in the care process was the source of yet further discrepant understanding in this study. These differences in opinion regarding the role of each in process are reflective of differing decision-making models as highlighted by Murray (2013). The current study added to this knowledge with the introduction of the prosthetists’ perspective. The prosthetists in this study suggest that in all cases they strive to ensure that the patients play an active role in the care process. This reflects a Shared Decision-Making model (Charles, Gafni, & Whelan, 1997) in which both parties share

information and have an equal input in any decisions. The experiences of the individuals in the current study however, conversely suggest that in the main the prosthetists are the facilitator within the process, with their own level of input being considerably varied. This implies a paternalistic model in which the prosthetist has control over any clinical decisions (Wirtz, Cribb, & Barber, 2006) or an interpretative model in which the prosthetists would take the patients' opinions and concerns into account but ultimately have the final decision (Emanuel & Emanuel, 1992). In either case, an incongruent understanding of the role of each party and the level of involvement in the care process is evident and should be addressed in future practice. The experiences of patients in the current study suggests that they feel neither included in the decision making process sufficiently nor do they feel sufficiently informed of any potential options available to them. In some cases individuals expressed the need to take the initiative to source alternative information, particularly with regards to technical possibilities. Concerns were raised regarding the discrepancy in information between those patients who had access to such alternative information and those who did not. This was seen to be reflective of an unbalanced or biased care system. That they had to search for such information in the first place was a source of frustration and resentment for some. Such discrepancies in the availability of such information should be addressed, particularly in terms of facilitating higher levels of patient involvement in the decision-making process.

Suggestions for future research

This study highlighted a number of areas for future research, most notably in the area of communication and shared understanding. Patients report the need for more information and involvement in the care process suggesting the need for increased communication and easier to understand information. Similarly, simply being listened to more was identified as a desired outcome. However, in this study the prosthetists perceived that they were meeting both of these requirements. An alternative explanation is that they are of the opinion that

they share as much information and involve the patients as much as is necessary for their needs. In either case there is a need to clarify the positions of each party and consider ways to implement a solution if such difference in understanding prevails. Given the apparent differences in perception of this interaction, more work is needed to understand it. Research focusing on the specific interactions between prosthetist and individual would be advantageous in order to identify where these discrepant understandings may occur and how this may be targeted. Similarly, as reports of the decision-making process appear to offer varied understanding as to the role of both the patient and practitioner in this relationship, further investigation of this would be appropriate. As has been previously investigated on a more general healthcare level (Ford, Schofield, & Hope, 2003), an investigation of the processes currently in place and that which would be preferred by both parties should be considered. Finally, given the importance placed on the availability of relevant information in the preparation for, and understanding of, the limb loss experience, the suggestion of the use of narratives should be considered. This could be implemented in a pilot study investigating the perceptions of such information of both individuals and prosthetists. Using these as an intervention prior to amputation, the impact on the post amputation experience could be assessed with a view to inclusion in clinical practice if successful.

Study limitations and researcher reflections

This study explored the perspectives of both patients and practitioners of the experience of limb loss and considered the implications for rehabilitation. While this has been achieved, aspects of methodological implications must be considered with regards to conclusions and potential for future study. Both patients and practitioners were asked to volunteer for this study on the basis that they wished to share their experiences with an awareness of the research aims of comparing patient and practitioner experiences. Such self-selection of participants may lead to biases in terms of the experiences which were shared. These may or may not be reflective of the wider population of individuals who have lost a limb or indeed

of prosthetists. While the individuals were recruited through a UK-wide advertisement which resulted in a wide geographic spread of participants, the prosthetists were recruited from 3 major centres in the central belt of Scotland. As such their experiences are likely to be reflective of the specific system in place in their geographic area without being necessarily representative of the wider National Health Service.

As would be expected, prosthetists' views were, in part, a reflection of NHS best practice policies. All were currently employed by the NHS and expressed a great deal of pride in the institution and the service which it provided. In some cases it was felt that the opinions expressed were given in such a way as to ensure appearing loyal to their employer and to this organisation in which they felt a great deal of pride. On some occasions such opinions were presented but then altered and became more personally relevant as the discussions continued. The ability to obtain a truly honest and objective opinion from individuals when being questioned in the role of an employee representative should be considered in terms of the implication on the experiences shared.

In terms of the individuals who had lost a limb, all but two responded to the call for participants stating a desire to tell their story in order to help others with their experiences. In the majority of cases they self-identified as being "high functioning amputees" and were keen to share their stories of achievement and overcoming adversity. Thus it is important to be aware of the limitations for wide ranging generalisations to be made on this basis. The use of such a method of recruitment could be criticised for not including individuals who struggle to respond to such requests and whose experiences may offer a different perception of poor outcomes. Similarly this study focused solely on unilateral, lower limb amputation. It is likely that variation would be found in the experiences of individuals who had lost upper or multiple limbs. Much of the focus of this study particularly in terms of social integration was the ability to "hide" the amputation if desired. With multiple or upper amputation this may be less practically possible leading to potential differences in both the personal and

social experiences of individuals in such circumstances. The use of hands and arms in daily social interactions lead to differing concerns for this group of patients which would not be present in a lower limb amputation sample.

IPA was selected for its potential to allow a subjective appreciation of the experience of a particular phenomenon. As the aim of this study was to investigate the perceptions of the experience of limb loss and prosthesis use this was considered to be appropriate. In addition IPA allows for the consideration of an individual's perspective on a phenomenon with the ability to make cross comparisons with other individuals. This made it ideal for the comparison of the views of the two groups in this study. IPA provides a rich, deep account of an experience which provided the level of knowledge that was intended in this study. A drawback of this technique however is the time consuming nature of the analysis given the level of interpretation and understanding that is sought. In addition the analysis is highly dependent on the skills of the researcher. As with other qualitative methods, the generalisability to a wider population of findings from an IPA study can be questioned. However, it was considered that the level of insight into the experience that this method can provide of the group in question is deep enough to justify potential transference to a wider population.

IPA requires a high level of researcher participation in the interpretation of the participants' experiences. This presents a variety of challenges for the researcher in being able to use one's own perspective within the interpretation but at the same time ensuring that the analysis is always embedded in the data. While conducting this study I, as the sole researcher, was aware of some of these challenges as they presented. My initial interest in the area of prosthetics and amputation stems from a family connection as my brother works in the area and we have had many discussions regarding the psychological implications of amputation. Similarly, I am also married to a General Practitioner and was aware of the potential to hold views skewed towards the medical profession. During the interview stages

of this process, I found it difficult to remain entirely impartial while conducting the interviews. While interviewing the individuals who had lost a limb I found myself wanting to empathise with them particularly when they shared experiences which were difficult for them. I also felt that I wanted them to sense that I was on “their side” so as to share their stories more openly. Similarly when interviewing the prosthetists I felt an affinity with a fellow health professional who often expressed frustration at the difficulties of working with a patient group and the challenges of maintaining a professional composure.

In the analysis stages I found it often difficult not to interpret the prosthetists’ experiences as being more reflective of the reality of the process when it was at odds with the experience of the individuals. I think this may be partially related to my background having family working in a variety of medical professions as leaning more towards a paternalistic, “doctor is right” opinion of healthcare. Ensuring that my analysis was reflective of the perceived realities of both groups and the recognition that a discrepancy between experiences did not make either less valid was a challenge which I worked to overcome. Similarly, it is possible that my previous work in the area and knowledge of some of the issues that have been raised in the past may have influenced my findings in this study. However, I strove to maintain a conscious awareness of this potential influence at all times and ensured that my findings were always transparently grounded in the data. This was further ensured by the regular assessment of my work by my two supervisors. I feel very strongly that IPA was the best methodology to use in this case and feel that the process of self-reflection and learning that I encountered while using it has made me a stronger researcher in the process.

Conclusions

This novel study addressed the perceptions of two separate but integral groups in the experience of limb loss, prosthesis use and rehabilitation. Both groups have a shared interest in the process of prosthetic limb fitting and rehabilitation and yet come from very differing perspectives. These differing perspectives have the potential to greatly influence the experience and outcome of this rehabilitative process and so facilitating a greater understanding of each stand point is essential.

The fitting and use of a prosthetic device is not a simple, technical process but rather involves a combination of psychological, social and practical components all of which much be recognized in the rehabilitation process. The prosthetists and individuals in this study each display a set of differing perceptions and expectations regarding the process itself, the device and each other. While these perceptions may produce a common theoretical framework, they do not always represent a shared understanding of the experience, despite the apparent best efforts of each party to comprehend the viewpoint of the other.

Communication issues within this dyadic relationship offer a central point for further development in both research and practice. It is at this level that the variation in understanding of the components of the experience comes to the fore. Through consideration of the interactions between individuals and prosthetists, recommendations could be made to improve shared understanding. Differing perceptions of the same system suggest a lack of integration of the understanding of each group in the process of rehabilitation. This offers potential for the targeting of specific areas of discrepant understanding and the explicit addressing of such areas through clinical practice and research. In this way, the experience of both prosthetists and individuals who have lost a limb are likely to become aligned, creating a more successful relationship in which to realise a positive, effective outcome for each party.

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Appendices

Appendix 1 – Interview Schedule, Individuals living with limb loss

Using a prosthetic limb.

- Can you tell me your experience of losing your limb?
- Can you describe to me your daily experience of living with amputation?
- Can you describe your experience of using a prosthetic limb?
- What impact has using a prosthetic limb had on your daily life?
- To what extent do you think of your prosthesis as being part of you?
Prompt – why or why not? What does this mean to you?
- What for you are the key things a prosthesis should provide?
- Is there anything you would like to add?

Appearance and ability (body image/prosthesis use)

- Tell me about how you look when wearing or not wearing your prosthesis.
Prompt-are you happy with it? Is there anything you would prefer to be different?
different?
- In what way does your appearance have an effect on your daily life?
- Can you tell me about your abilities when wearing or not wearing your prosthesis?
Prompt- are you happy with it? Is there anything you would prefer to be different?
- Can you tell me about how physically happy you are with your prosthesis
- Can you tell me about how you feel wearing your prosthesis

Expectations

- Can you tell me about your expectations of amputation and how these compared to your experience?
- Has your experience changed as time has gone on?
- In an ideal world what would you like your prosthesis to provide?
Prompt: functional ability, appearance, comfort, social acceptance?
- Is there anything you would like to add?

Appendix 2 – Interview Schedule, Prosthetists

Interview questions (Prosthetists)

Using a prosthetic limb.

- In general, what do patients report of their experiences using a prosthetic device?
- Do you find this varies between patients e.g. gender, reason for amputation?
- Are there any common reports of things that patients like or dislike about their prosthesis?
- In your experience, what impact does wearing a prosthetic limb have on a patient's life?
- Can you tell me about whether or not patients consider their prosthesis to be part of them?
- What do you think are the key factors of a prosthetic device in order for it to be fully accepted by the patient?
- Is there anything you would like to add?

Body image (Function vs. Aesthetics)

- What do your patients report about appearance both with and without their prosthesis
- What do your patients report about ability both with and without their prosthesis
- What do your patients report about the physical comfort/satisfaction of wearing their prosthetic limb?
- What do your patients report about the emotional comfort/satisfaction of wearing their prosthetic limb?
- Can you tell me your experiences of patients expressing any preference of appearance vs function?
- Is there anything you would like to add?

Expectations

- Are there any typical expectations of patients prior to amputation in term of living with limb loss?
- How realistic do you think these expectations are?
- Do you find that their expectations and experience changes over time? In what way?
- What factors would you say have an effect on this?
Prompt: reason for amputation, level of preparedness prior to amputation
- In an ideal world what do you think the prosthesis should provide?
Prompt: functional ability, appearance, comfort, social acceptance?
- Are there any ways in which you think this varies with patient e.g. age or gender?
- Is there anything you would like to add?



Queen Margaret University

EDINBURGH

Living with Limb Loss

My name is Clare Uytman and I am a PhD student from the Department of Psychology at Queen Margaret University, Edinburgh, undertaking a research project entitled “Living with Limb Loss”

This study will investigate the individual experience of living with limb loss as well as the experience of those working in the field of prosthetics.

I am looking for volunteers to participate in the project. Participants should be over 18, and have had an amputation for more than 6 months or have a congenital missing limb.

You can choose to take part in either a one hour interview with me or an interview via email.

If you would like to participate or for more information please contact me:

Clare Uytman

cuytman@qmu.ac.uk or 0131474000

Thank you.

***Appendix 4 – Information sheet for Individuals living with amputation,
Face to face interviews.***



Queen Margaret University
EDINBURGH

“Living with limb loss”

Project Information Sheet

My name is Clare Uytman and I am a PhD student from the Department of Psychology at Queen Margaret University in Edinburgh. For my PhD I am undertaking a research project entitled “Living with limb loss: A qualitative investigation of the experience of living with limb loss from both the individual and prosthetist perspective”

This study will investigate the individual experience of living with limb loss as well as the experience of those working in the field of prosthetics.

The findings of the project will give a valuable insight to the experience of those living with limb loss and also allow a comparison of potential similarities and discrepancies with those working in this area. This may allow for suggestions to be made in terms of clinical practice and teaching.

I am looking for volunteers to participate in the project. Participants should be over 18, and have had an amputation for more than 6 months or have a congenital missing limb.

If you agree to participate in the study, you will be asked to take part in a short interview with the researcher. The researcher is not aware of any risks associated with this interview. The whole procedure should take no longer than 60-90 minutes although this will vary from participant to participant. You will be free to withdraw from the study at any stage and you would not have to give a reason.

All data will be anonymised as much as possible, but you may be identifiable from tape recordings of your voice however only the research team will listen to these recordings. Your name will be replaced with a participant number, and it will not be possible for you to be identified in any reporting of the data gathered.

The results will be published in the final PhD thesis and also may be published in a journal or presented at a conference.

If you would like to contact an independent person, who knows about this project but is not involved in it, you are welcome to contact Mr Duncan Robb. His contact details are given below.

If you have read and understood this information sheet, any questions you had have been answered, and you would like to be a participant in the study, please now see the consent form.

Contact details of the researcher

Name of researcher: Clare Uytman,
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Department of Psychology,
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Contact details of supervisor:

Name of supervisor: Prof. Chris McVittie
Department of Psychology,
School of Social Sciences, Media & Communication,
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Contact details of the independent adviser:

Name of adviser: Mr Duncan Robb, Head of Division.
Department of Psychology,
School of Social Sciences, Media & Communication,
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EH21 6UU

Email / Telephone: drobb@qmu.ac.uk / 0131 474 0000

***Appendix 5 – Information sheet for Individuals living with amputation,
Email interviews.***



Queen Margaret University
EDINBURGH

“Living with limb loss”

Project Information Sheet

My name is Clare Uytman and I am a PhD student from the Department of Psychology at Queen Margaret University in Edinburgh. For my PhD I am undertaking a research project entitled “Living with limb loss: A qualitative investigation of the experience of living with limb loss from both the individual and prosthetist perspective”

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I am looking for volunteers to participate in the project. Participants should be over 18, and have had an amputation for more than 6 months or have a congenital missing limb.

If you agree to participate in the study, you will be asked to take undertake an email interview with the researcher. The researcher is not aware of any risks associated with this process. The process of interview will involve you being emailed a series of questions and may involve additional follow up emails. The process should involve approximately 4 return emails although this will vary from participant to participant. You will be free to withdraw from the study at any stage and you would not have to give a reason.

All data will be anonymised as much as possible. Your name will be replaced with a participant number, and it will not be possible for you to be identified in any reporting of the data gathered.

The results will be published in the final PhD thesis and also may be published in a journal or presented at a conference.

If you would like to contact an independent person, who knows about this project but is not involved in it, you are welcome to contact Mr Duncan Robb. His contact details are given below.

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Email / Telephone: cuytman@qmu.ac.uk / 0131 474 0000

Contact details of supervisor:

Name of supervisor: Prof. Chris McVittie
Department of Psychology,
School of Social Sciences, Media & Communication,
Queen Margaret University,
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EH21 6UU

Email / Telephone: cmcvittie@qmu.ac.uk / 0131 474 0000

Contact details of the independent adviser:

Name of adviser: Mr Duncan Robb, Head of Division.
Department of Psychology,
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Queen Margaret University,
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EH21 6UU

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Queen Margaret University

EDINBURGH

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I am looking for volunteers to participate in the project. Participants should be fully qualified prosthetist, registered with the Health Professions Council

You can choose to take part in either a one hour interview with me or an interview via email.

If you would like to participate or for more information please contact me:

Clare Uytman

cuytman@qmu.ac.uk or 0131474000

Thank you.

Appendix 7 – Information sheet for Prosthetists, Face to face interviews.



Queen Margaret University
EDINBURGH

“Living with limb loss”

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I am looking for volunteers to participate in the project. Participants should be fully qualified prosthetist registered with the Health Professions Council

If you agree to participate in the study, you will be asked to take undertake a short face to face interview with the researcher. The researcher is not aware of any risks associated with this process. The process should take approximately 60-90 minutes although this will vary from participant to participant. You will be free to withdraw from the study at any stage and you would not have to give a reason.

All data will be anonymised as much as possible, but you may be identifiable from tape recordings of your voice however only the research tem will listen to these recordings. Your name will be replaced with a participant number, and it will not be possible for you to be identified in any reporting of the data gathered.

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Appendix 8 – Information sheet for Prosthetists, Email interviews



Queen Margaret University
EDINBURGH

“Living with limb loss”

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I am looking for volunteers to participate in the project. Participants should be fully qualified prosthetists registered with the Health Professions Council

If you agree to participate in the study, you will be asked to take undertake an email interview with the researcher. The researcher is not aware of any risks associated with this process. The process of interview will involve you being emailed a series of questions and may involve additional follow up emails. The process should involve approximately 4 return emails although this will vary from participant to participant. You will be free to withdraw from the study at any stage and you would not have to give a reason.

All data will be anonymised as much as possible. Your name will be replaced with a participant number, and it will not be possible for you to be identified in any reporting of the data gathered.

The results will be published in the final PhD thesis and also may be published in a journal or presented at a conference.

If you would like to contact an independent person, who knows about this project but is not involved in it, you are welcome to contact Mr Duncan Robb. His contact details are given below.

If you have read and understood this information sheet, any questions you had have been answered, and you would like to be a participant in the study, please now see the consent form.

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Appendix 9 – Project Consent Form



Queen Margaret University
EDINBURGH

“Living with limb loss”

I have read and understood the information sheet and this consent form. I have had an opportunity to ask questions about my participation.

I understand that I am under no obligation to take part in this study.

I understand that I have the right to withdraw from this study at any stage without giving any reason.

I agree to participate in this study.

Name of participant: _____

Signature of participant: _____

Signature of researcher: _____

Date: _____

Contact details of the researcher

Name of researcher: Clare Uytman,
PhD Student,
Department of Psychology,
School of Social Sciences, Media and Communication,
Queen Margaret University,
Edinburgh.
EH21 6UU

Email / Telephone: cuytman@qmu.ac.uk / 0131 474 0000

Appendix 10 – Project ethical approval original documentation

Application for Ethical Approval
2009/2010 Academic year



Queen Margaret University
EDINBURGH

APPLICATION FOR ETHICAL APPROVAL FOR A RESEARCH PROJECT

This is an application form for ethical approval to undertake a piece of research. Ethical approval must be gained for any piece of research to be undertaken by any student or member of staff of QMU. Approval must also be gained by any external researcher who wishes to use Queen Margaret students or staff as participants in their research.

Please note, before any requests for volunteers can be distributed, through the moderator service, or externally, this form **MUST** be submitted (completed, with signatures) to the Secretary to the Research Ethics Committee.

You should read QMU's chapter on "Research Ethics: Regulations, Procedures, and Guidelines" before completing the form. This is available at:

<http://www.qmu.ac.uk/quality/rs/default.htm>

Hard copies are available from the Secretary to the Research Ethics Committee.

The person who completes this form (the applicant) will normally be the Principal Investigator (in the case of staff research) or the student (in the case of student research). In other cases of collaborative research, e.g. an undergraduate group project, one member should be given responsibility for applying for ethical approval. For class exercises involving research, the module coordinator should complete the application and secure approval.

The completed form should be typed rather than handwritten. Electronic signatures should be used and the form should be submitted electronically wherever possible.

Applicant details

1. Researcher's name: Clare Uytman
2. Researcher's contact email address: cuytman@qmu.ac.uk
3. Category of researcher (please tick and enter title of programme of study as appropriate):

QMU undergraduate student	
Title of programme:	
QMU postgraduate student – taught degree	
Title of programme:	
QMU postgraduate student – research degree	
QMU staff member – research degree	x
Living with Amputation: A qualitative investigation of the experience of living with amputation from both the individual and prosthetist perspective.	

QMU staff member – other research	
Other (please specify)	

4. School: SSMC
5. Subject Area: Psychology
6. Name of Supervisor or Director of Studies (if applicable): Dr Chris McVittie
7. Names and affiliations of all other researcher who will be working on the project:
Dr Joanne Fox - psychology

Research details

8. Title of study: **Living with Amputation: A qualitative investigation of the experience of living with amputation from both the individual and prosthetist perspective.**
9. Expected start date: November 2009
10. Expected end date: Approximately April 2013
11. Details of any financial support for the project from outside QMU: N/A
12. Please detail the aims and objectives of this study (max. 400 words)

To provide a detailed qualitative account of the subjective experience of living with limb loss from the individual's perspective as well as considering the views of those working in this field. This project will consist of two studies examining the experience of individuals living with amputation and prosthetists. These studies will be compared in order to identify areas of shared importance and/or discrepancy that may then inform clinical practice and to gain a subjective understanding of this experience from both groups. In addition, this study will use both email and face to face interviews allowing further comment to be made on the benefits and drawbacks of each methodology.

Methodology

13. Research procedures to be used: *please tick all that apply.*

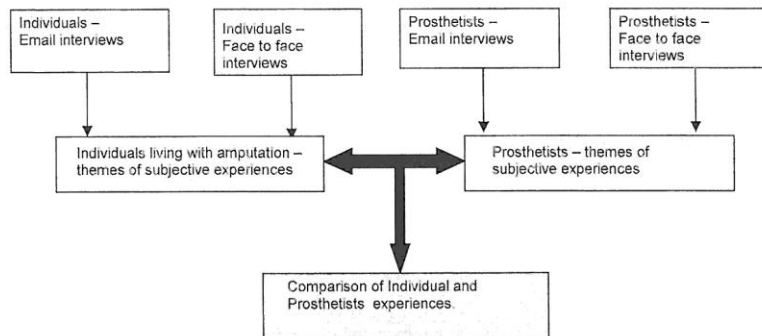
	Tick if applicable
Questionnaires (<i>please attach copies of all questionnaires to be used</i>)	x
Interviews (<i>please attach summary of topics to be explored</i>)	x
Focus groups (<i>please attach summary of topics to be explored / copies of materials to be used</i>)	
Experimental / Laboratory techniques (<i>please include full details under question 14</i>)	
Use of email / internet as a means of data collection (<i>please include full details under question 14</i>)	x

Use of questionnaires / other materials that are subject to copyright (please include full details under question 14 and confirm that the materials have been / will be purchased for your use)	
Use of biomedical procedures to obtain blood or tissue samples (please include full details under question 14 and include subject area risk assessment forms, where appropriate)	
Other technique / procedure (please include full details under question 14)	

14. Briefly outline the nature of the research and the methods and procedures to be used (max. 400 words).

This project will consist of a series of semi structured interviews conducted either face to face or via email. 2 groups of participants will be recruited. 40 individuals living with amputation will be recruited via support and user groups throughout the UK or online support forums. My intention is to recruit 20 male and 20 female participants who will be then further divided into 10 email and 10 face to face interviews. This will allow comment to be made on not only the methodology used for interview but also previously contested differences in experiences based on gender. 20 prosthetists will be recruited via personal contact and national prosthetic centres. These will also be subdivided in to 10 interviews via email and 10 face to face again to allow comment on the methodology. The interviews will be semi structured using an interview schedule based on questions in such areas as the experience of living with amputation, using a prosthetic device and issues of appearance and ability (see attached sample question sheet). A similar line of questioning will be used for both groups. The data gathered will be analysed using Interpretative Phenomenological Analysis (IPA) (Smith; 1994, 1996, 2004). IPA is particularly concerned with the individual's experience of a particular event within their own world. Living with limb loss is an inherently personal in individual experience. In addition the factors involved with adjustment and rehabilitation to this new experience are particularly complicated and involving multifaceted constructs such as body image and self concept. This suggests that a qualitative approach such as IPA which allows the detailed examination of such an individual experience would be appropriate. This project will consist of analysis of four data sets: Individuals living with amputation and health professionals interviewed both via email and face to face. Firstly separate analysis of each data set will be performed. This will be followed by a comparison of face to face versus email interviews in each sample. Finally a comparison of the two groups will be considered (see diagram 1)

Diagram 1: Flowchart of Analysis.



15. Does your research include the use of people as participants? *Please delete as appropriate.* **Yes**
16. Does your research include the experimental use of live animals? *Please delete as appropriate.* **No**
17. Does your research involve experimenting on plant or animal matter, or inorganic matter? *Please delete as appropriate.* **No**
18. Does your research include the analysis of documents, or of material in non-print media, other than those which are freely available for public access? *Please delete as appropriate.* **No**
19. If you answered 'Yes' to question 18, give a description of the material you intend to use. Describe its ownership, your rights of access to it, the permissions required to access it and any ways in which personal identities might be revealed or personal information might be disclosed. Describe any measures you will take to safeguard the anonymity of sources, where this is relevant:

This text box will expand as required.

20. Will any restriction be placed on the publication of results? *Please delete as appropriate.* **No**
21. If you answered 'Yes' to question 20, give details and provide a reasoned justification for the restrictions. (See Research Ethics Guidelines Section 2, paragraph 7)

This text box will expand as required.

22. Will anyone except the named researchers have access to the data collected? *Please delete as appropriate.* **No**
23. Please give details of how and where data will be stored, and how long it will be retained for before being destroyed. (See Research Ethics Guidelines Section 1, paragraph 2.4.1)

All Data will be anonymised and stored in conjunction with the 1998 Data Protection Act and QMU guidelines. All data will have all personal identifying information removed and stored in either the onsite electronic (eResearch, QMU Research Repository: <http://eresearch.qmu.ac.uk/>) and physical data repositories. All raw data will be retained for a period of 5 years or until the project is completed and award granted. All consent forms will be retained for the same period within the Psychology Subject Area.

24. Please highlight what you see as the most important ethical issues this study raises (eg. adverse physical or psychological reactions; addressing a sensitive topic area; risk of loss of confidentiality; other ethical issue. If you do not think this study raises any ethical issues, please explain why).

The most important ethical issues raised by this study are the addressing of sensitive topic areas and potential for adverse psychological reactions to the topics discussed.

25. If you have identified any ethical issues associated with this study, please explain how the potential benefits of the research outweigh any potential harms (eg. by benefiting participants; by improving research skills; other potential benefit).

Potential benefits if this research included a greater understanding of the experience of individuals living with amputation as well as the opportunity for exploring the similarities and discrepancies in the views and experiences of prosthetists. Considering the views of both groups will allow suggestions to be made which may in future inform clinical practice and lead to a more positive and individually centred care approach for both patients and professionals. In addition participants will be given to express their opinions and share their experiences which in itself may be a potentially positive experience for them. This study has the potential not only to comment on the methods used but also to add to the limited body of evidence available in qualitative research in this specific population. This would be the first study of its kind to address issues from both the point of view of the individual and prosthetist.

Protection for the Researcher

26. Will the researcher be at risk of sustaining either physical or psychological harm as a result of the research? *Please delete as appropriate.* **No**
27. If you answered 'Yes' to question 26, please give details of potential risks and the precautions which will be taken to protect the researcher.

This text box will expand as required.

Research Involving Human Participants

You should only complete this section if you have indicated above that your research will involve human participants.

28. Please indicate the total number of participants you intend to recruit for this study from each participant group:

Participant Group	Please state total number
QMU students	
QMU staff	
Members of the public from outside QMU	60
NHS patients	
NHS employees	
Children (under 18 years of age)	
People in custody	
People with communication or learning difficulties	
People with mental health issues	
People engaged in illegal activities (eg. illegal drug use)	
Other (please specify):	

** Please declare in section 32 where the participant group may necessitate the need for standard or enhanced disclosure check*

29. Please state any inclusion or exclusion criteria to be used. (See Research Ethics Guidelines Section 1, paragraph 2.4)

Group 1: Individuals living with amputation
Inclusion Criteria: Must be over 18 and have had the amputation at least 6 months prior to amputation. Amputation must be unilateral, lower limb.
Group 2: Prosthetists.
Inclusion Criteria: Must be qualified Prosthetist registered with the Health Professions Council.

30. Please give details of how participants will be recruited:

Group 1: Individuals living with amputation (20 male, 20 female)
Participants will be recruited via online forums and through personal contact with support groups throughout the UK. Online forum invitation will involve contacting the moderator of the site then posting an invitation message on the forum notice board. Support group recruitment will involve initial contact with named chair of group followed by invitation letters sent to each group requesting contact if suitable.
Group 2: Prosthetists (20)
Prosthetists will be recruited via personal contact with individuals via email or invitation phone call.

31. Please describe how informed consent will be obtained from participants. (See Research Ethics Guidelines Section 1, paragraphs 2.1.2 – 2.1.5)

All participants will be judged as being capable of fully and freely giving informed consent. Anyone suspected of being unable to do so will be excluded from the study. A full written explanation of the study including who is involved in the research, the purpose of the research, what is expected of the participants and reassuring them of their right to withdraw at any time, assured confidentiality and that their participation in this study is in no way connected to any care they are receiving (in the case of the individuals). Participants will be given the opportunity to ask any questions they may have either verbally or via email. Face to Face participants will then be given an informed consent form to sign before interviews will commence. Email participants will be emailed a copy of the same consent form and asked to read and indicate if they agree with the statements before interviews will commence.

32. Ethical Principles incorporated into the study (please tick as applicable):

	<i>Tick as applicable</i>
Will participants be offered a written explanation of the research?	yes
Will participants be offered an oral explanation of the research?	Yes when using face to face interviews
Will participants sign a consent form?	yes
Will oral consent be obtained from participants?	Yes when using face to face interviews
Will participants be offered the opportunity to decline to take part?	yes
Will participants be informed that participation is voluntary?	yes
Will participants be offered the opportunity to withdraw at any stage without giving a reason?	yes
Will independent expert advice be available if required?	yes
Will participants be informed that there may be no benefit to them in taking part?	yes
Will participants be guaranteed confidentiality?	yes
Will participants be guaranteed anonymity?	yes
Will the participant group necessitate a standard or enhanced disclosure check?	no
Will the provisions of the Data Protection Act be met?	yes
Has safe data storage been secured?	yes
Will the researcher(s) be free to publish the findings of the research?	yes

If the research involves deception, will an explanation be offered following participation?	N/A
If the research involves questionnaires, will the participants be informed that they may omit items they do not wish to answer?	N/A
If the research involves interviews, will the participants be informed that they do not have to answer questions, and do not have to give an explanation for this?	Yes
Will participants be offered any payment or reward, beyond reimbursement of out-of-pocket expenses?	No

Declarations

33. Having completed all the relevant items of this form and, if appropriate, having attached the Information Sheet and Consent Form plus any other relevant documentation as indicated below, complete the statement below.

- I have read Queen Margaret University's document on "Research Ethics: Regulations, Procedures, and Guidelines".
- In my view this research is:

See Research Ethics Guidelines Section 6	Please tick
Non-invasive	x
Minor invasive using an established procedure at QMU	
Minor invasive using a NEW procedure at QMU	
Major invasive	

- I request Ethical Approval for the research described in this application.

Name (if you have an electronic signature please include it here)



Date 3/12/09.

Documents enclosed with application:

Document	Enclosed (please tick)	Not applicable (please tick)
Copy of consent form(s)	x	
Copy of information sheet(s)	x (x4)	
Sample questionnaire	x (x1)	
Example interview questions	x (x1)	
Copy of proposed recruitment advert(s)		
Letters of support from any external organisations involved in the research		
Evidence of disclosure check		
Subject area risk assessment documentation		

Any other documentation (please detail below)		

34. If you are a student, show the completed form to your supervisor/Director of Studies and ask them to sign the statement below. If you are a member of staff, sign the statement below yourself.

- I am the supervisor/Director of Studies for this research.
- In my view this research is:

See Research Ethics Guidelines Section 6	Please tick
Non-invasive	<input checked="" type="checkbox"/>
Minor invasive using an established procedure at QMU	<input type="checkbox"/>
Minor invasive using a NEW procedure at QMU	<input type="checkbox"/>
Major invasive	<input type="checkbox"/>

- I have read this application and I approve it.

Name (if you have an electronic signature please include it here)

Christine Date 3/12/09

35. For all applicants, hand the completed form to your Head of Subject or Head of Research Centre or, if you are an external researcher, submit the completed form to the Secretary to the QMU Research Ethics Committee. **You should not proceed with any aspect of your research which involves the use of participants, or the use of data which is not in the public domain, until you have been granted Ethical Approval.**

FOR COMPLETION BY THE HEAD OF SUBJECT / HEAD OF RESEARCH CENTRE

Either

~~I refer this application back to the applicant for the following reason(s):~~

Name (if you have an electronic signature please include it here)

Head of Subject / Research Centre

Date _____

Please return the form to the applicant.

Or

Please tick **one** of the alternatives below and delete the others.

~~I refer this application to the QMU Research Ethics Committee.~~

~~I find this application acceptable and an application for Ethical Approval should now be submitted to a relevant external committee.~~

I grant Ethical Approval for this research.

Name (if you have an electronic signature please include it here)

 _____

Head of Subject / Research Centre

Date 3/11/09.

Please send one copy of this form to the applicant and one copy to the Secretary to the Research Ethics Committee, Quality Enhancement Unit, Registry.

Date application returned: _____

Appendix 11 - Examples of development of subthemes and master themes from individual data.

Example 1: “Sam”, Individual living with amputation.

Exploratory coding	Emergent themes	Subtheme	Master theme
New self vs. Old self. New aspects of self arising from amputation. How I look vs. what I do. What really matters to me? Future self Redefining self Where do I fit now? Who am I now? Self determination Emotional preparedness Got to get on with it!	Views of self Functional vs. Appearance Self definition Renegotiation of identity Attitude and rehabilitation	Identity Following Amputation Defining Normality Individual attitude and adjustment	Personal Identity
Views of others Perceptions of strangers Influences on thoughts Vulnerability How do I fit in now? Reliance on family Dependence or independence? Reassurance	Social me Social comparison Perceptions of others: real and presumed Social support	Social interactions Social Support Social Comparison	

Peer support	Peer support: meaning and worth		
Comparison and Motivation			
Disability: What does that mean?	Impact of prosthesis use	Living with the prosthesis	The Prosthesis
Function	Realities of prosthesis use		
Activity			
Spontaneity			
Impact on life			
Control by device	Controlled by prosthesis		
Relationship with device	Integration into life	Expectations of prosthesis use	
Positive/negative aspects of limb use			
Disappointment			
Expectation vs. reality	Expectation vs. Reality		
Function = Independence = SUCCESS!	Priorities	Priorities for prosthesis use	
Technological advances			
Understanding the process	Involvement (or lack of)	Prosthetist and patient interactions	Communication
Who makes the decisions?			
Choices and options			
No choice really – What else is there but to agree?	Controlled vs. involved		
Information – I had no idea what was going to happen!	Information (or Lack	Expectations of the system	

Trusting the medics	of)		
Emotional preparedness	Roles of professional	Role of the prosthetist	
They don't understand!			
Inequality in care	Recognition of needs		
Inconsistency in care	Perceptions of care system		

Example 2 : “Eve”, Prosthetist.

Exploratory coding	Emergent themes	Subtheme	Master theme
Reaction to amputation	Self categorisation	Identity Following Amputation	Personal Identity
Merging old self with new	Redefining self	Defining Normality	
Adjusting to new “reality”			
Redefining themselves	Returning to normality		
Self categorisation			
Getting back to “normality”	Appearance vs. function	Individual attitude and adjustment	
Its what they think of themselves that counts			
Returning to pre-amputation self	Patient attitude		
Appearance vs. function			
Mind-set of patient			
Determination to succeed			Social Identity
Reaction of others	Presenting self to others	Social interactions	
Fitting in			

Limitations/blaming the device Technological solutions Finding the best outcome Clinical focus	Limiting technology		
Involvement of patients Patient led service Choice and acceptance Patient responsibility Perceptions of system Perceptions of NHS Patient expectations Trust Relationship with patient Multiple roles of prosthetists Psychological issues	Communication Information Decision making Patient expectations Managing expectations Relationships and roles	Prosthetist and patient interactions Expectations of the system Role of the prosthetist	Communication

Appendix 12 - Additional illustrative excerpts from data

Example 1: Prosthetists

Personal Identity	
Identity following amputation	<p>He fell into the category of ‘I’m now disabled’. And he would live, I’m sure now I haven’t seen that patient for a good number of years, but I’m sure he’s still in that situation and he’ll continue to live in that situation until such time as someone takes his benefits from him and he maybe has to go to work but I couldn’t understand why this chap was so happy to do that (Chris 142-146)</p> <p>For most people I think the problem is coming to terms with a physical limitation: “Oh, now I’m disabled” and I think that’s a very difficult thing because it’s never coming back, you never get better and so they obviously have this physical limitation for ever and I think it’s that that can get people down. They know they’re not going to get better. (Eve 46-50)</p> <p>Like I had a young guy that came in and he wanted to be able to carry his young baby up the stairs, that was what his first aim was and you knew from his age, that it was a trauma, that he’d no other health problems, that was an achievable goal. He can now run about and play football with his toddler so. Other people it might be, somebody older it might be just that they want to potter about at home or out in the garden (Kate 114-119)</p>
Individual attitude and adjustment	<p>He’s definitely very mature, but again I think, not so much the human mind, but I think the person and the person’s personality (Mike 411-412)</p> <p>the guy’s hands were so bad and elbows were so bad you thought, there’s no way he could put a prosthesis on and he did it. It took him half an hour every time but he did it because he was very, very determined and, you know, if only every patient was like that our life would be a lot easier (Chris 262-265)</p> <p>I suppose it’s maybe the mindset of the patient that it’s their determination that says: Well, I want to be doing this and it’s maybe a</p>

	way of getting over their loss themselves. They find a focus(John 243-245)
Defining normality	<p>Basically to return to what they would conceive as everyday life,normality , for want of a better word and again , this is where it becomes a bit more difficult because it's individual (...) It can be quite difficult, you know to satisfy, everybody's needs and expectations but more often than not there's either like a handy tool or something you can do in order to make it easier. (Mike 567-560)</p> <p>Because I had a patient that had been involved with a lot of research to do with Mio electric limbs and I was looking at a lot of her paper cuttings and one of the quotes that she had in it was that it's not going to give her a normal life because she had that before, it's just going to make things easier and I thought that ...I really like that quote, because, what's normal? (Kate 601-605)</p> <p>There are other occasions , for example the sort of fitting and delivery appointments where the patient's limb is been finished off, where they would want to maximise the cosmesis of their limb by having it finished to a nice shape and on other occasions other patients talk more in general about their life as an amputee ,about sitting on the floor with their grandchildren and how, being an amputee, stops them from doing that or they have to take a limb off in order to do that and so on, so , it really does vary from one patient to the next (Chris 12-17)</p>
Social Identity	
Social interactions	<p>People report on comfort, fit, alignment/gait, limping, appearance, weight, what their families think about the leg. (Anne 16-17)</p> <p>I mean there have been patients who have said to me things like "Well my husband has never seen my limb" So they would take the leg off somewhere else in the house or the dark or whatever and that was always an interesting situation which I wouldn't have pursued it any further but the comment has been occasionally been said by some older amputee a lady who I think was just coming</p>

	<p>from post war time. And relationships have moved on in married lives, I mean it's different so I think there's things there too (Steve 456-462)</p> <p>It had to be as good as it could be made for them and a lot of time can go into doing that because they express the opinion that they are conscious of the shape where they are conscious that other people are looking at their prosthesis and they want it to be as good as possible. (Steve 524-529)</p>
Social support	<p>Sometimes the family will be saying things that sound like they're helping but they might actually be putting more onus on the patient themselves and putting them a bit under pressure by saying : Oh, you'll be up in two weeks and walking no bother and all that kind of thing, so they then come to us and say :Oh, I'll need to be up in two weeks because my wife needs me (John 77-88)</p> <p>Again, the younger people tend to have a bigger support network, friends and family so they tend to ,although they can go through a difficult time , they tend to improve, whereas a lot of older people , perhaps they don't have as much support , especially if they have a bereavement, you know their spouse dies or something like that, they just never, never recover so a lot of older people, it happens to, are maybe a bit more on their own anyway find it much harder to get to a state of mind that helps them focus on the positive (Eve 348-353)</p> <p>say a husband comes with his wife and the wife's there listening but maybe the husband's brother will say something like that who hasn't been part of any of the conversations . Now, if the patient himself knows the reality but he feels that he is getting pressure, it's not meant to be (...) They are trying to encourage but it turns out it's actually making them feel worse about it (John 94-99)</p>
Social comparison	<p>They can wear their trousers and look down. You know, two shoes there and that makes them feel, maybe that they are not so different from everybody else (James 289-290)</p>

	<p>You know and it's sometimes things like that that make you realise it's your body image because you don't want people to see you without a leg on because they'll realise you're an amputee (....)so his main concern then that he didn't want to appear as an amputee to other people . He's happy to walk about with crutches (...)People think he's just got a sore leg (Kate 548-356)</p> <p>I suppose there's one girl that's about 18 and she is, I'd say it's bordering on affecting the function it's so cosmetically- her socket's been made so tight that the trim lines are flush to her, you know ? It's pinching in a wee bit and I'll say: well, I'll need to flare that out and she's saying: Well, I don't want that because it'll look worse (Kate 190-194)</p>
The Prosthesis	
Expectations of prosthesis use	<p>People have this expectation: I'll get my leg and you'll never see me again and that's a common one (James 476-477)</p> <p>Again a lot of our patients are older , they have lots of other illnesses to deal with and they have an expectation: "Oh, I've lost my leg but they'll give me a new one and I'll be fine" and what people don't understand is that they physically have to make this limb work and it's never as good as their own limb and comes with a lot of other problems as well, so the expectations of what people think they'll be able to do and what they can feasibly do are often way off (Eve 264-269)</p> <p>I sometimes find they've got quite high expectations , especially recently with all those things on the media . They see these young soldiers and they think they'll just be able to get up and run (Kate 8-10)</p>
Living with the prosthesis	<p>you do get some patients that they're not that bothered about walking. It's just about getting out They would be happy in a wheelchair but they might need a limb (...) for transfer and things. Well you do get some people who...one lady just wanted to be able to go to the bingo, which she still does in her wheelchair and she doesn't wear her limb much but she's always got that option she can put it on (...) If she wants to look good if she's out, you know, she's got two</p>

	<p>limbs (Kate 130-137)</p> <p>they have this inanimate object in front of them that they can focus on and sort of blame for everything else that is going wrong with them (James 207-208)</p> <p>But I think that accepting that it's part of them is quite important and I don't know for sure how to answer that but my perception of it would be patients who are coping really really well with it are it's part of them . It's something they put on in the morning as they would do with other things, their shoe or their watch or whatever it is just something else that they use (Angie 573-577)</p>
Priorities for prosthesis use	<p>I think it's maintaining their independence so their ability to get into and out of the bathroom by themselves , take a shower, to get in and out of their house to take a taxi so they can get out to go into town, to go to the bingo , to see their friends . (Eve 416-418)</p> <p>I think a prosthesis should be comfortable , as comfortable as it can be , obviously it's an artificial limb, it's not their own limb so there's always going to be slight issues with comfort and that's something we'd have to educate and say :Well, it's supposed to take pressure here, it's pressure, it's not pain , so it's managing that (John 606-609)</p> <p>From my point of view it's meeting their needs and goals and expectations whatever they are . For most, If I have to give you an actual answer I would say to get people back to the lifestyle and the activities that they did before, maybe with limitations but if they can do what they did before, perhaps in a different but still engage in things that they enjoy I think that's probably, if I can tie it down (Eve 518-521)</p>
Communication	
Prosthetist and patient interactions	<p>I certainly wouldn't impose anything on to patients. It's for them to tell me what they want , not for me to tell them what they're getting . Definitely not (Mike 701-703)</p> <p>That the patient has almost to take a bit of responsibility for their care . You know if I ask a patient what hobbies do you do and he</p>

	<p>just ignores me , well that's going to make my job harder so I'll have to start with something basic and see how it goes from there , whereas if the patient says : I do this, this , this and that it points me in the correct direction (Mike 251-254)</p> <p>And I think they don't take ownership and I think that you only get out of a situation what you put in and maybe health care professionals are reluctant to actually instil that into people and I think they have far too much of a cotton wool (Nicola 324-326)</p>
Expectations of the system	<p>There are some limitations in terms of the real high-definition cosmesis , the bespoke work and our patients would have to go private if they wanted that. There is an element of choice there that if they did want to have that need to go private if they wanted that £4000 cover on their leg then that's not something that the NHS can provide and some of the real high-spec components as well but in the majority we provide a real wide range of components and most of our patients should manage fine on them (Angie 515-520)</p> <p>they don't normally express opinions about where they want to get to although it is important to discuss what reasonable outcomes will be with them so that , if they do have expectations that they haven't expressed , they have some idea about where we're going in this treatment programme and that should be done by any professional so that folk know roughly where we're taking them (Steve 241-245)</p> <p>Yes, well, you do get a lot, the majority of patients are ...you get on fine with them . You know there's not much. They're happy with their limbs . Because they always say that 10% of your caseload's 90% of your work and I think it's true and it's maybe the folk that are difficult, not difficult, but they maybe have some problems with that are in their head (Kate 550-553)</p>
Role of the prosthetist	<p>When they're here , when they first have an amputation and obviously it's a terrible time and they go through a process and we do have a certain amount of help , not a specific psychologist which I feel we should have,</p>

	<p>because we're not experts in this area but just through experience and talk and communication they go through the change process and they try to come to terms with things so we can help them in the way that we can just by listening to them and whatever although I think a professional would be better (Eve 50-56)</p> <p>You know people will phone you up as if you're an old friend and: "Oh, how are you doing. I've not seen you in a year or so. This limb you've made me is really good but it's starting to creak a bit. Is it O.K. if I come in" and I'd say: "Yes, no problem, come in" and when those relationships do build up you know (Mike 171-174)</p> <p>There are those kind of people who don't engage . You know they're not going to turn round to their G.P. and say : You know, I'm feeling really depressed . They're not going to do that. They need us I think to try and step in a little bit (...) they're going to struggle too much and these are kind of the older gentlemen who don't like taking tablets , they don't like to bother people , but you know that they're suffering from depression and anxiety and they haven't been out the house for a few months and again we get a lot of their problems because they literally haven't anybody else to talk to (Eve 357-364)</p>
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Example 2: Individuals with amputation.

Personal Identity	
Identity following amputation	<p>My mind just totally scrambled, I just sort of, it's kind of weird because you can't make sense of it. I wasn't upset, I was just kind of thinking - shock and just a bit about myself as well (Gareth 35-37)</p> <p>I was in training for the squadron athletics at the time when I lost my leg and that was a thing I had to come to terms with - it was very upsetting.(Patrick 255-257)</p>

	<p>And ehm, so it took me a wee while to get over that I think just looking at myself, nae kids and I sort of felt like half the person that I was if you know what I mean. Loads of things going through my head you know like body image, they used that quite a lot and I suppose I was like how Fiona would see me, like being in bed together or that and just a few things like that (Sam 232-236)</p>
Individual attitude and adjustment	<p>He said “you’ll wake up at nights wanting to cry saying Why Me?” I was like that, oh I’ve that to face have I? but I’ve never had that. And people say to me aw it’s just your attitude, you’ve got the right attitude but the attitude I took was right this is what I’ve got, the leg’s no going to grow back on, forget about it. Continue your life with what you’ve got (Jim 141-144)</p> <p>I think people thought I was coping very well because I achieved all that but once it was achieved, I thought, well that’s it, you just have to get on with it now (Gareth 316-317)</p> <p>you just get on with it, it’s all you can do. It’s either that or you just crawl into a hole somewhere and make your life miserable - it’s not worth it. I am positive, I do whatever I can, just live independently. (Gayle 66-69)</p>
Defining normality	<p>For me it meant going back to work because I had got a limb. Trying to get a job when you are permanently in a wheelchair is incredibly difficult. (Penny 87-88)</p> <p>well at the end of the day, you miss the company but then again, do you remember an old Monkee’s song from the 70’s, Daydream believer? Susan Boyle has done it. There’s a brilliant line in it “the 6 O’clock alarm never rings” I says Where I, I was like everyone else, you moan about going to your work but once you are up and you are there, you enjoy it, you’ve got your company (Jim 250-253)</p> <p>Yes, I’m really delighted that I can still do things like golf (...) It’s one of the</p>

	<p>games that you can. I really thought when I lost my leg that I would be in a wheelchair when I was 50. (Patrick 347-357)</p>
Social Identity	
Social interaction	<p>It [his role as a dad] changed. I couldn't take him camping obviously but I got other parents to take him camping as well and quite often after school, a lot of kids came round to our house when I was there so obviously in a child minding role. (Neil 163-165)</p> <p>I can understand why people might say, do you not feel more human with the leg on but it's like saying, that's of less importance to me what people think of me when they see me. Well you have to think, you've become the tall guy with the moustache to becoming, you are now the guy with one leg and that's what defines you. (Gareth 377-380)</p> <p>well at the end of the day, you miss the company but then again, do you remember an old Monkee's song from the 70's, Daydream believer? Susan Boyle has done it. There's a brilliant line in it "the 6 O'clock alarm never rings" I says Where I, I was like everyone else, you moan about going to your work but once you are up and you are there, you enjoy it, you've got your company (Jim 250-253)</p>
Social support	<p>Yes, all that support was a major plus. I mean when I was at Dunfermline, there was a recreational room where you could take your visitors so they would come into the ward and I would take the wheelchair and we would go and there were another 5 guys in the ward and they were quite envious of he number of visitors I had (Andy 287-289)</p> <p>The night before the amputation, I didn't want to talk to anybody. There was a nurse there from Botswana who I really got on with before that and she sat and talked to me for about an hour and I said I don't want to see anybody because they</p>

	<p>don't know how it feels (Gareth 62-65)</p> <p>My wife and I used to go away at the weekends to hotels, nearly every weekend in the good weather. When she died, I definitely went down hill a wee bit when she died (Craig 154-156)</p>
Social comparison	<p>Well when I initially went in, obviously there were other patients who went with me. Some had lost 2 limbs so when you see something like that, you always think that you are a lot better off (Tom 222-224)</p> <p>I'm maybe more fortunate than other people that I can get around with the wheelchair and I don't have to put the prosthetic on all day so I suppose has got to be a benefit. (Stuart 437-439)</p> <p>I didn't feel I had anything in common with this person at all. He was a double amputee and had a motorised wheelchair, came through from Glasgow. I don't know, I just didn't gel with him so I didn't really see that he understood anything (Gareth 462-465)</p>
The Prosthesis	
Expectations of prosthesis use	<p>I was desperate to have a shot. Desperate because again I thought: Ooh, I'm going to show off and I found it so difficult to walk in that as well but I think I still just thought that somehow it would, you know (Holly 524-526)</p> <p>Standing up after being in a wheelchair for 2 years was fantastic and initially all I wanted was to walk. (Penny 44-45)</p> <p>In terms of my walking ability, I thought it would be more than what it is but I think it's that people don't understand what that feels like attached to your body but on the other hand, when this isn't on, this stump feels different from what I thought it would feel like. (Gareth 536-539)</p>
Living with the prosthesis	It means I can do what I want to do to a

	<p>large extent. If I was to visit somebody in a top floor flat, I would have to ask them to come down to visit me. So it's just making adjustments (Neil 145-147)</p> <p>If you look at an elderly person who is an amputee, you would probably would think about the restrictions of what they can and can't do but an awful lot of restrictions are up here [indicates to head]. It's not about I can't do it but more about how am I going to do it. The direct route that you did before is maybe not going to be quite right but you can get there but just a wee bit jiggling around (Gayle 198-202)</p> <p>I've got no problem walking and I'm fortunate really - I think it was a really good amputation. They said to me in hospital, that's a really good amputation you've had. But nevertheless, that doesn't mean that you don't get abrasions. It has actually transformed my life. (Sean 137-140)</p>
Priorities for prosthesis use	<p>Oh I like the comfort right enough, and the appearance doesn't bother me because it's covered all the time. I don't know what they could do quite honestly. I mean they've went as far as they can go as far as I'm concerned. I'd like it a wee bit more normal looking you know? (Craig 339-341)</p> <p>I suppose first and foremost actually, it should fit very well – that's the most important - that's in the wrong order really. The fit is all important and if you get a badly fitting prosthesis, it's like wearing a pair of wellingtons that are 3 sizes too big and you wonder how the heck you are going to keep them on. (Penny 535-541)</p> <p>It even has the vague shape of a leg because the cosmesis across there I don't think is any great shakes but I just want to get my comfort. (Holly 474-475)</p>
Communication	

Prosthetist and patient interactions	<p>I hope that is the case throughout the amputation world. The relationship I have with (name) has been first class. He's been adaptable, he's been open to suggestions, you know, he's not had a closed mind, he'll try other stuff and he's always been proactive in prescriptions for higher activity legs (Tim 500-503)</p> <p>Some want to hear and find out everything and others don't want to know any of it but most people are so grateful (...) they want to get you out of the way so they can ask silly questions – you know, what are the staff like, what's the funding like, what's it going to look like – all these things – what they really want to know and if more centres were doing that, I think that would help with the emotional side for many more amputees. (Penny 470-481)</p> <p>One of the things that surprised me when you first lose your leg is, how do you find a comfortable position to sleep, where do you put your leg and it does feel quite uncomfortable and it catches on your sheets [I - And you're not used to any of that?] No so I think that's the sort of things that you never really understood before and what that would be like (Gareth 552-559)</p>
Expectations of the system	<p>And that's what really gets me down - there is no sense of urgency with these - well they are not medics, they are professions allied to medicine is the academic term (Danny 175-176)</p> <p>And I know there's probably everybodys like that but it just feels like either there's no enough prosthetists or I dunno they just kinda...I feel like they are great when you are there and they're all for this and that and then it feels like when you go away you get the feeling like that's just going to get put to the back of the drawer and then. (Sam 321-324)</p> <p>I know there's things like , if you want an appointment at the Astley and everybody</p>

	wants an appointment tomorrow and you can't get it , that's the reality but from a new liner to getting a new socket over there is taking two months (Holly 568-570)
Role of the prosthetist	<p>I think there's a bit of sort of, he does know much more than me, you know (Holly 670)</p> <p>I've had other prosthetists there because (name) might be on leave and before (name) there was another girl called (name) who is also very good but she went on maternity leave so I haven't always been with (name) but the level of all of them has been very good even when (name) can't see me (Tim 254-257)</p> <p>The trouble is that they don't seem to know what people feel when they have an amputation because they are endlessly asking for volunteers for research, if you get phantom pain. (Gareth 547-549)</p>